# **BENZO JUNKIE**

### More than a case history

# How Doctors and Drug Companies Get Us Hooked

by

**BEATRICE FAUST** 

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to David Jones and the Toucans

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Survival is a privilege which entails obligations.	

Survival is a privilege which entails obligations.

Simon Wiesenthal

Wherefore seeing we also are compassed about with so great a cloud of witnesses let us lay aside every weight, and the sin which doth so easily beset us, and let us run with patience the race that is set before us

Hebrews 12:1 King James Version

# PREFACE: A WORLD SPLIT OPEN

What would happen if one woman told the truth about her life? The world would split open.

Muriel Rukeyser, 'Kathe Kollwitz'

The light is bright in my room I can see all the way to the window. I look through the slats of my cot. Not painted. The bright leaf green carpet stretches for miles - all the way to the window No curtains - just a pulled down blind. The lampshade is horrid. White. Glass. Like a little chinaman's hat. Nothing in the room beside my cot and me. The door opens and there is Dr. Mute. I must be sick.

This is my first memory. It is a portent. It is of a doctor. With asthma, then bronchiectasils and finally arthritis, I have been a consumer of medical services all my life.<sup>1</sup>

In 1982, I was prescribed Ativan, one of the benzodiazepine family of tranquillisers. I spent the next five years in a state of misery, chasing a new, pervasive and mysterious illness that doctors could not diagnose. When I halved my dose preparatory to stopping the drug, my suffering worsened. I did not know it, but I had precipitated withdrawal syndrome. Eventually, I identified what was the matter with me: I had been addicted.

The discovery rocked me with pukka shame! Me - of all people! How could this have happened to me? I wanted to recover and get on with my life but I knew I was morally obliged to write something on this miserable and embarrassing episode for the sake of others still addicted and those who might be saved by making the scandal of tranquilliser addiction even more public than it already is.

I thought I could get away with a feature article.

When I told friends and colleagues, they responded to the news much as they did thirty years ago when I stated publicly that I had had three abortions: 'You of all people! How could you ...?' One senator even said to me 'Well, I believe you because it's you. I didn't believe all those other people on the *Couchman Show!*' So I had to write about my own defeat for the sake of all those other people.

George Orwell thought that a truthful biography was impossible 'because every life viewed from the inside would be a series of defeats too humiliating and disgraceful to contemplate.' What defeat could be worse for a fiercely autonomous woman than to succumb to doctor-induced drug addiction? And to be defeated, not even by going into hospital and coming out addicted to morphine or pethedine, but by voluntarily taking a banal tranquilliser in the prescribed dose at the prescribed intervals under the supervision of a banal doctor!

The shame of revealing one's defeats is not the only problem with biography. There is the delicate question of how far to be truthful in the face of other taboos, how far to implicate my friends and loved ones, how far I may embarrass my political allies - feminists, civil libertarians, sex reformers, and benzo survivors.

I considered writing a disinterested, general account of the benzo experience, selecting only those features that I share with other survivors. But since my story is unique in a multitude of ways, the differences are as important, perhaps more important, than the similarities.

I was not a stereotypical distressed pill-popper. In 1982, my first book, *Women, Sex and Pornography*, was highly esteemed and selling well. My marriage had passed its tenth anniversary and was chuffing along quite merrily. My talented son was an adolescent - but I expected him to recover. My health was degenerating at less than the rate predicted for a lifelong asthmatic. I thought my career was secure.

I was not prescribed Ativan for anxiety, or for the normal stresses of life or even for a condition, like asthma or heart disease, that is believed to have a stress component. I was seeking treatment for a mood swing that had been a handicap for the previous five years but had been more or less controlled, pending a cure, by Transcendental Meditation and yoga.

I resisted the drag of addiction with all the forces I had developed to resist the drag of illness. I did not stop writing. Although I can identify several pieces that were exceptionally difficult to write, due to addiction sickness, I do not believe that anyone who regularly read my photography criticism for the Melbourne *Age* or my occasional book reviews and feminist comments would have said 'she's going off! I wonder if she's stoned?' Even with hindsight, no one has pointed to chapters in *Apprenticeship in Liberty* that display withdrawal psychosis.

Having survived a divorce and relocation, and the greater grief of my son's dropping out of academia, I entered the nine-to-five workforce almost simultaneously with entering withdrawal: indeed, the daily responsibility distracted me from my sufferings.

The challenge of learning new mechanical skills like word-processing engaged me when I couldn't think straight. Regular eating and sleeping habits, and disciplines like yoga and TM, kept me stable, while my considerable research capacity turned up startling facts about doctors, drugs and detailers. My long networking experience helped me to find my way around the politics of the problem.

I could not depict the horror of benzodiazepine addiction by reducing my experience to a hypothetical average and leaving out my distinguishing personality.

If I had had an average education, I would not have done the research that convinced me I could not describe the pharmaceutical industry and the medical profession in a feature article. If I had been averagely healthy, I would not have the vast experience of doctors that is the basis for the second half of the book. If I had not enjoyed a long flirtation with politics, I could not presume to tell society what it does not want to hear.<sup>3</sup>

This book, then, is more than a case history but less than an autobiography. It is as frank as it can be without implicating my son, my recently ex-husband, my sexual partners, my friends and colleagues. I use my personal experience as a resource but I am describing only one facet of my life.

The first half of the book is mainly derived from documents and published research. My only excuse for repeating the work of such stalwarts, as John Braithwaite<sup>4</sup> is that they have not been listened to.

Over the last two decades, I have kept two types of diaries. One was intermittent, lengthy, detailed self-analysis whenever I wrestled with a particularly burdensome problem. The other is regular short jottings to remind me of daily happenings. Whenever I try a new drug or try to understand the course of an illness, I note doses and symptoms. Otherwise, I do not record my illnesses or medicines.

I used these diaries to construct the detailed outline of my story that was published in the submissions to the House of Representatives Standing Committee on Community Affairs Inquiry into Prescription and Supply of Drugs.<sup>5</sup> They are also a major source for the second half of this book.

The story is not one hundred per cent accurate - many agonies went unrecorded in the diaries because I did not realise that they were part of a pattern but, as I move between the details that are recorded, I recall the contents of the absences. What was written down often functions as a mnemonic for what was left out.

Sometimes I missed a tiny detail - for example, when I was tallying my experience of benzodiazepine before Ativan, I missed a Mogadon prescription. I believe the mistakes are venial - it takes a good few mothholes to prevent us seeing the pattern in a paisley scarf.

Four years of searching for justice with lawyers have proved to me that I am more likely to get justice - or, at least, satisfaction - by writing about injustice. I already knew that injustices are only righted when those who have never suffered by them are as affronted as those who have.

### CHAPTER 1 SCRIM

In the middle of the journey of our life I came to myself in a dark wood where the straight way was lost ... So bitter is it, that scarcely more is death ... I cannot rightly tell how I entered it, so full of sleep was I about the moment that I left the true way.

Dante Alighieri

You asked about my experience of benzodiazepines. The first five encounters were trivial. The sixth was indescribably awful. I was prescribed Librium once for weeping and once for asthma. I was prescribed Valium once for asthma and once for anxiety. I was prescribed Mogadon for sleeplessness. These drugs did me neither good nor harm and I stopped taking them after a decently compliant interval. Then I took Ativan.

I could say that my life went askew like a linen tablecloth carelessly dried on a clothesline. I could say that sinking into addiction and struggling through detoxification was like playing my life always on the wrong side of a scrim. I could say that for five years I lived behind ambulance glass.

In Boris Vian's play, *The Empire Builders*, there is a curious character, wrapped like a mummy, called the Schmerz - 'pain'. His sole function is agonising. I could say that I became a schmerz - pained in body and mind because of a drug that assaults that nexus of mind and body, the brain.

The benzodiazepine family of drugs affects the limbic system and the cortex by interfering with a neurotransmitter and a receptor very similar to those affected by alcohol. Since they hit two of the body's main chemical messenger systems - the neurotransmitters and, indirectly, the endocrines - there is no physical or mental process that can resist their impact. They have been the subjects of major controversy ever since their introduction in the 1960s, stimulating Congressional hearings in the United States, and in Great Britain, they are now the subject of a bigger round of litigation than thalidomide.

It should be common knowledge that as little as one month on drugs like Serepax, Valium and Ativan can cause addiction, that the

addiction sooner or later leads to substantial physical and mental breakdown, and that the withdrawal is many times worse than withdrawal from nicotine or heroin - if only because it can take many years for the body's systems to regain their balance. Recovery becomes increasingly impossible in the elderly.

To become a benzo junkie is to become pain.

That is the subtle effect.

As for the crude ones ... I had myself tested for diabetes and liver disease, syphilis and AIDS. There is no test for multiple sclerosis. By the time spontaneous bruising had become so obvious as to merit concern, I had discovered what was the matter with me - and it was not leukemia. In between, I had a tooth restructured, had my eyes tested, my hip X-rayed, my abdomen palpated and my womb curetted. I had an endoscopy and a simple neurological workup. I tried to get a lithium test and a brain scan. I wondered if it could be Altzheimer's? a brain tumour? bad genes? For over two years I was afflicted by a dreadful sense that something was wrong with me and an obsessive determination to find out what it was. I went from the desultory pursuit of single symptoms as they arose to a frantic pursuit of It.

I was told that I was malingering, hysterical, menopausal and ... too clever for a woman.

Having come through, I can assure you that benzo withdrawal is more benign than benzo sickness and that withdrawal undergone with the support of kind, well-informed helpers is no harder than any other form of convalescence - every withdrawal symptom means that you are detoxifying and that is itself enough to let you experience the symptoms positively.

My story is very simple. In 1977, I was prescribed theophylline for asthma. It caused The Horrors but the benefit to my breathing, my sleeping, my arthritis and my spirits was so great that I clung to it, and tried to remedy the panic. I was prescribed Stematil, then Amitriptyline and Valium. No effect. I tried biofeedback but that only worked when I didn't have The Horrors. I tried Ativan. It worked.

My story is very complicated. I was born with asthma and had probably developed Bronchiectasis by the end of my first year. The scoliosis that I had developed by the age of nine or ten had become kypho-scoliosis with osteo-arthritis from the cervical to the lumbar

vertebrae by the time I was thirty. A psychiatrist once told me that, with my problems, I'd be crazy if I weren't depressed.

However, I cannot explain my depression as simply a rational response to poor health. It is probably endogenous - arising from within. There is alcoholism, suicide, depression, neuroticism, and domestic violence in the three lines of my family that I know anything about.

I am not concerned to speculate on my heredity but to show that the whole of my life had been passed in a state of ill-health and compliance with doctors. When the various symptoms of benzo poisoning emerged in relentless succession, I did not appreciate that they represented a new and vastly different problem from anything I had experienced. I had an existing framework to interpret them by. I explained the depressed breathing by the rotten state of my lungs, the joint and muscle pain by my arthritis, the lowered resistance by my general debility. The menorrhagia was ascribed to age and the emotional fog to the interaction of constitutional vulnerability with the stresses of being Beatrice Faust.

In 1982, when I began taking Ativan, I was forty-three. I had a rigid regimen that included about forty minutes' yoga, thirty minutes' meditation, sundry pills and a compressed air pump to vaporise asthma solutions. I also had a disposition to keep regular hours and to eat whole foods as far as possible without being puritanical. I think this regimen helped me to accommodate the benzo debility and to structure my life to withstand its undermining effects.

I had also, by then, endured five years of the anxiety that I called The Horrors. Kafka called it The Fear. Virginia Woolf called it The Wave.

I would wake up - usually every second day but sometimes on consecutive days - overwhelmed by a sense of dread. For no reason. It was as natural and inevitable as rain on the roof. It was inside me. As I toughed it out, the tension would ease towards dinnertime. On alternate days - sometimes for several days together - I'd wake feeling buoyant, sanguine, my best self I had no trouble getting to sleep but could not stay asleep for more than three or four hours.

Ativan made me fall in love with my face in the bathroom mirror. Ordinarily, the only way I'd look as good as that would be with a new and marvellous lover. With Ativan, I looked my best self. It erased all

my pain and tiredness, sorrow and stress. Like a bacchante, I laughed over my shoulder at my image in the mirror. I told my friends that I had discovered a wonder drug. That I would not be ashamed to stay on it for the rest of my life. That I had become whole.

How long did it last? I cannot remember. I do know that in 1985 I spent ten days in the world's second best hotel and that every other day I lived like an automaton - ventilated, exercised, showered, fed at regular intervals, and with The Horrors at my back I thought it was because my marriage was breaking up.

The first symptom that told me I had acquired a new sickness was a dreadful stink. Initially, I thought it was the Vaseline I'd been using to keep my leather dress supple. When I realised that it was in fact on my breath and in my sweat, I began a tedious round of doctors.

Kind friends advised me to use perfume, drink lots of water, and watch my diet. They placed me alone on one side of the dinner table or invited me to take afternoon tea in the garden. Strangers recoiled and cruel people talked about me behind my back.

The stink was actually a symptom of advanced addiction. I had had many earlier symptoms but had not recognised them.

The first was menorrhagia. my periods lasted as long as twenty-three days. The bleeding was so heavy that I felt as if I were passing a kilo of chicken livers, sensing large clots slipping through my cervix as quietly as ghosts. I bought Tampax and Modess in the largest sizes and the heaviest weights at Coles for efficiency and economy. The girls on the cash register used to cluck and coo as they handed me my parcel and say 'It's awful, isn't it?' Curettage and hormone replacement therapy did not help. I refused a hysterectomy and toughed it out until menopause supervened.

Next came nursing mother randiness. My normal sexual style is masculine: I am visually aroused most of the time, although I have a weakness for vibrant voices and hair I can run my hands through. I prefer strong, intelligent, laughing men and athletic, performance-oriented sex. I expect every encounter to include at least one orgasm. That was transformed to a diffuse, never-ending state of arousal, totally inward turned, without any urge to climax or, for that matter, any need to seek physical contact. I lapsed into fantastic dreams of romantic love - the most enduring being a passion for Tom Conti in his role as Colonel Lawrence.

Then my libido disappeared almost entirely. I both knew this was because of the pills and yet forgot the fact. At times I became a bit sad when I thought that the killjoys who said that sex becomes boring if you have too much of it might be right.

A severe, unidentified pelvic pain became the third substantial warning that something was radically wrong. It was like an ectopic pregnancy. I thought that it might be an adhesion from my sterilisation. I did not ask how adhesions could appear after a ten-year interval. I thought it might be referred pain from my arthritic spine. Once more, investigations revealed nothing. Once more, I toughed it out.

Then came a series of little neurological symptoms - a tic in my left eyelid, clumsiness, dropping things and tripping over my feet, falling over. This went with an obsessive need to chew which I indulged by eating a packet of Vita Wheet at a sitting. When the sickness was in its penultimate stage, this became chewing cupfuls of uncooked rice. No, I didn't have syphilis, and no, Ativan does not cause tardive dyskineasia. In any case, my symptoms were not the same kind of chewing as that melancholy disorder of the too-long sedated.

I had an episode that looked like a slight stroke in which my right side was paralysed for a couple of hours. It was labelled Transient Ischaemic Attack. For over two years, whenever I bumped into people, or walls, or furniture, or fell over while getting out of a tram, I blamed the TIA. That's how I explained away biting my lips and the inside of my cheeks and becoming unexpectedly tongue-tied. I never asked how these symptoms could persist so long after their putative cause. Partly, I was set on being well, on functioning as best I could. Partly, benzos were making me slow-witted and passive.

I lost my concern for self-preservation and became enormously stoical, accepting risks and insults that would normally have stirred my adrenaline.

I had episodes of severely depressed breathing that were quite unlike either asthma or bronchiectasis. It was as if I kept forgetting to breathe. Since I could, by focussing my entire attention on the matter, force myself to breathe deeply and rhythmically, and since it did not escalate into an asthma attack, I tended to forget about it except when I found that I could not control my breathing to lecture effectively. My voice emerged flat and wooden and colourless.

This was actually the most serious of all my symptoms. People with bronchiectasis need to cough regularly or they drown in their own secretions. In hindsight, I realise that the prolonged and severe lung infections that caused me so much misery and were the despair of my physiotherapist, were related to depressed breathing and the inability to cough.<sup>2</sup> My poor paralysed lungs were breeding infection and I could not help myself by yoga or anything else. Who knows how I survived?

I was beginning to look very ill. My hair became brittle and flyaway, my face became pudgy and my complexion dull. I stared into the mirror and looked for me in the image of the haggard stranger with my face. People started standing up for me in the tram. Gossips told each other that Bea Faust was getting seedy. Some of my friends thought I was dying.

I had the occasional hallucination - which I called optical illusions because they were so trivial and transient. I'd never tried hallucinogenic drugs and I had no frame of reference for these experiences. My vision became blurred and I fiddled interminably trying to orient my eyes and my glasses to read clear print. I quickly learned to make do with fuzzy. I felt enormous pressure inside my skull when I lay down to sleep. My limbs jerked in response to sharp pains, as if I'd been bitten by a giant stainless steel mosquito. Once I glimpsed the skin when this happened and the follicle had risen up like a huge, isolated goose pimple - as if a nerve had fired randomly.

I had a pain like barbed wire across my diaphragm and this did not relate to digestion or breathing. It was just a pain - nothing to take a pill for but curiously unlike anything I had ever known. Nothing about benzo sickness or withdrawal is like anything I've ever known - although some other survivors say benzo withdrawal is near as a touch to the DTs.

Sleep it is a blessed thing beloved from pole to pole . . . for years, I had used Transcendental Meditation to get to sleep. It had been a wonderful prophylactic. I told myself that the somnolence that increasingly overtook me was due to this facility developed by meditation. I fell asleep over the dinner table in Mietta's and told myself it was because I was bored by the *ne culturny* conversation of my husband's colleagues. Eventually, I was so worn down that I could prop myself anywhere and sleep for hours.

Sometimes, by contrast, I seemed to speed up, finding myself chattering manicly. Or my handwriting would run out of control and

crowd itself up into a comer of the page. I put too much chocolate in the mousse and had extraordinary difficulty following a simple knitting pattern. At other times, I could think clearly and rapidly and even more aggressively than usual.

I lost my sense of taste for many things and developed a curious catlike fastidiousness about food, unable to eat anything rich or greasy. This had nothing to do with nausea or gastric upset. It was a profound revolt against denatured food. I was more and more drawn to the simple subtleties of Japanese cuisine. I had a similar aversion to tea, coffee and alcohol. Whenever I became convinced that I was losing my sense of smell and taste, I would find that I could identify various aromas and I decided I worrying needlessly.

These exquisite symptoms were accompanied by gross ones: my mouth sometimes filled spontaneously with viscous saliva - and I mean filled - I could spit half a cup or a wine glassful at a time. I also had a sensation as of moisture at the comers of my mouth. I dabbed obsessively when I was eating, but when I looked in a minor for the dribbling, there was nothing to be seen. My feet seemed to stick tackily to the bathmat or the carpet even when they were quite dry.

I developed muscular stiffness and rigidity so severe that intercourse and even gynaecological examinations were difficult. Orgasm was terribly laborious and sometimes I suffered from cramps for as long as thirty hours afterward. It was as if any strong movement would lock my muscles in a painful after-image of activity. The muscles seemed to retain a chemical memory of what they had been doing. Occasionally, I'd be sitting in the tearoom talking about nothing in particular and I'd find my pelvis and thighs contracting orgastically.

Often the slightest effort was enough to give me electric shocks in my joints. Arthritis? Rheumatism! I began to favour my limbs to avoid these various miseries. I disposed my body carefully when I sat down. I developed something that I called hard insomnia: it was as if every cell in my body was alert and defied sleep. Meditation did not relax me but I did it dutifully because I am a dutiful person and I was desperate. I judiciously used alcohol to get me to sleep - on good nights one ounce of spirits knocked me out. I never increased that dose.

Nor, in all this time, did I increase my dose of Ativan. That would have been against my lifetime habit of following the doctor's instructions. Since I related all my symptoms to other causes, I had no reason to use anti-anxiety medication for them. A friend tried to warn

me that these pills were dangerous and, in my gullible arrogance, I assured him that lorazepam (Ativan) was not the same as diazepam (Valium). Neither of us knew that it is, in fact, much worse.

I knew that I needed my pills and that I'd suffer if I missed one but I thought that was because the absence of the pill simply revealed the presence of the problem it was meant to cure. I never considered that I might be addicted - not even after the time I missed a pill and woke up ga-ga. I read an article about pharmaceutical drug addiction but, since it was full of cliched human interest and had no salient information, I did not identify with any of the people interviewed. The significance of the discussion of Valium penetrated my stupor in a very peculiar way.

I somehow lurched through divorce and relocation. Finding myself alone on the first day of the rest of my life, I decided that I had no real excuse for being on happy pills that were, in any case, too expensive.<sup>3</sup>

I halved my dose in March 1988. All of the neurological symptoms became worse. And the hallucinations. Life became anxiety. A simple photography review took three or four times as long as it should have. I knew that I had to do everything very carefully or there'd be a dreadful snafu. I scanned my work for errors, I double checked references. I organised my daily routines like computer programmes so that everything led into everything else.

I restructured my house to create a mnemonic web where I could shift things around so that they would be seen and not forgotten. I had always been the sort of person who made lists - shopping, things to do today, things to do next week. I depended on my lists. I used the kitchen timer to help me keep a real grasp on time.

I was beset by a prolonged, high-pitched ringing in the ears that lasted for almost a year. Flinders Street traffic at peak hour might drown it out and a couple of hours spent laughing with a friend could cure it for an equal period of time, but it seemed a permanent part of my life - indeed, it is now vying with the hum of the computer as I type. At times my eyes spurted acid tears that dried in fine powder on my glasses. The ground undulated beneath my feet. I could not get my key into the lock without steadying one hand on the other. I became ambidextrous; making my left hand do more work because my right hand was doing less. I suffered waves of weakness so great that a few coins placed in my hand by the market lady weighted it down like lead. I never knew when I picked my handbag up whether it would feel heavy or light. I became paranoid, watching other people laughing and talking

and imagining they were looking at me - just as people do in the textbooks.

I became hypersensitive to noise and light. I saw myself living like an eccentric with most of the house in semi-darkness and silence, preferring to water the garden at night. I nearly ran out of *Ben Hur* but I was frightened of falling over the balcony of the Concert Hall in the dark.

My skin would not tolerate the ribs on winter pantyhose or the weight of bedclothes. I dreaded shaking hands with people in case their fingernails brushed my skin. My own nails were pain enough. I drank compulsively and urinated to match. I touched furniture, walls, rails as I walked to offset vertigo.

All through this nightmare, words kept running through my head. 'I took Valium. It did nothing for me. I stopped it overnight. I am not an addictive personality... tried Valium ... nothing for me ... stopped overnight ... Valium... overnight ... not addictive personality.'

Somehow the penny dropped. It was not Valium but Ativan! I had been made a pharmaceutical junkie!

I rang the first emergency number I could find in the phone book - Alcohol and Drug Problems Direct Line. I had the best diagnostic interview I have ever enjoyed and within ten minutes I was in touch with TRANX. It was nice to know I was not the only survivor, nice to discuss the dreadful business with others who had been there.

Soon after my first support group meeting, when I was having difficulty quartering a tablet, I gave up in rage and disgust. I threw the lot down the loo. I had been on the pills daily for five years and had come off in three and a half months. I'd kicked the habit practically before I knew that I had one.

Once I had a name for what ailed me, my symptoms became more manageable. I was not going mad. I was not going to die. I was going to detoxify.

My health returned even while the withdrawal symptoms were still unfolding. I became anorexic but energetic. I was restless and had brief episodes of agoraphobia but my muscle tone improved and I stopped bumping into things. The feelings of cobwebs over my face and

wetness no longer irritated me although I never got used to conjunctivitis and blurred vision.

I tried to accelerate my recovery but found that there is no methadone for benzos. However, an article on radiation sickness yielded a hint that did give some relief: readily available amino acids and vitamins are precursors of neurotransmitters. I began taking tryptophan and nicotinamide and I recommend them heartily.

Innocence gives me strength. Benzodiazepine addiction is nothing to be ashamed of. It is not a matter of an addictive personality but of pharmacological insult for which we are not to blame.

I consigned my benzos to the sewer in Spring 1988. I am writing this in Lent 1989. As I write, I have the sensation of something chewing my ear. It is a familiar sensation - almost friendly. The point about withdrawal symptoms is that they are signs of returning health.

## CHAPTER 2 MORE THAN A CASE HISTORY

Why me? Why not?

Anon.

If I had gone to a doctor and said 'I'm on Ventolin, Becotide, Brufen, paracetamol, antibiotics and heroin', any sensible practitioner would have said 'Steady on! ... Run that past me again!' During the years 1982-87, I trailed from doctor to doctor seeking help with a series of unfamiliar and disturbing symptoms. I gave each of them the cause of my illness (es) in the second item of my case history.

- 1. Existing illnesses: asthma from birth; bronchiectasis (lower lobes, both lungs) from age twelve months; scoliosis from age nine; kyphoscoliosis from age forty (?); osteo-arthritis from the cervical to the lumbar vertebrae diagnosed at age thirty but definitely present from age twenty-six-probably earlier; lifelong intermittent depression. Outpatient at mega-hospital for sixteen years.
- Medication: 1ml. Ventolin solution by nebuliser once daily (twice if very ill or on days of high pollution), six puffs Ventolin and eight puffs Becotide by aerosol, 400mg Brufen three times daily, paracetamol and various antibiotics as needed, 2.5mg Ativan nightly.

That none of the thirty or so GPs and consultants ever did query the Ativan is proof of the ignorance and complacency of the medical profession, the effectiveness of pharmaceutical marketing, and the negligence of government.

Cross-tolerance between chlordiazepoxide, the first benzodiazepine to be sold, and barbiturates and barbiturate-like drugs had been demonstrated in 1960, the same year that Hoffman-La Roche released chlordiazepoxide under the trade name Librium. Also in 1960, benzodiazepines were shown to relieve withdrawal symptoms of barbiturates, barbiturate-like drugs, and alcohol. That is, the benzodiazepines were potentially as addictive as these drugs.

Furthermore, they were known to be definitely addictive in both high and medium doses but the lowest threshold for addiction had not been established. In other words, there was no known safe dose. By 1984) after more than twenty years of warnings, the World Health Organisation had convinced the UN Commission on Narcotic Drugs to schedule thirty-three different benzodiazepines, including Ativan, as addictive. 2

Now, the friendly neighbourhood GP may not have known these facts - even by 1982 when I was first prescribed Ativan/lorazepam or by 1987 when, without knowing that I was addicted, I gave it up. However, I was not prescribed the drug by a GP but by a psychiatrist in a university unit at a teaching hospital. This was during the time when twenty years of unfavourable research and ten of consumer agitation had forced drug companies to begin providing slightly expanded information coyly suggesting that the benzodiazepine family of drugs

- could give rise to dependence,
- was not suitable for long-term use,
- was not suitable for pregnant women, the aged, the debilitated or people with pulmonary deficits, and
- should not be given to depressed patients because of the suicide risk.

I had had asthma from birth and bronchiectasis from about the age of twelve months, leaving me with about two-thirds of normal lung capacity at best; at my worst, I have about half. Certainly by the age of four and probably much earlier, I had developed anaclitic depression that later merged gradually into adult depression. My spine had begun to twist by the age of nine and osteo-arthritis was diagnosed when I was thirty. In 1982, I was forty-three years old and the prescribing doctor, who also had a flourishing sideline as an expert medical witness, said I would be on Ativan for the rest of my life. My addiction, then, must be seen against a background of life-long illness.

Benzodiazepine addiction is not self-indulgent, like an addiction to chocolates; it is not even comforting, like an addiction to nicotine. With addictions such as nicotine and heroin, the drugs are taken to avoid withdrawal symptoms: with benzodiazepines, sufferers endure withdrawal symptoms while still taking the drugs. The only vaguely comparable experience would be the use of drugs to torture political prisoners in Soviet psychiatric hospitals.

Even that analogy is not quite apt because torture by doctors working for the secret police in a totalitarian state is at least intelligible: torture by doctors in a democracy who have a duty of care towards their patients is not. To be abused by someone we trust is more hurtful than to be abused by strangers or enemies.

Benzodiazepines are arguably effective in quelling anxiety or inducing sleep for a short time - sometimes as short as two weeks and rarely as long as four months. As the patient becomes tolerant of the drugs - that is, as the drugs become ineffective - they begin to create the symptoms they are meant to cure so that the patient suffers from intensified anxiety or insomnia.

Unless the victim increases the dose, s/he becomes quite sick, quite soon with a variety of new and apparently unrelated symptoms. The sickness is more cruel with newer versions of the drug that are eliminated more quickly from the body - the short-acting benzodiazepines.

My addiction must also be seen against a background of life-long compliance with doctors. I am such a refractory patient that I like to cooperate whenever it is reasonable to compensate for all the times I feel obliged to exercise my own judgement. Having so many things wrong with me complicates the task of isolating the effect of any particular treatment.

Do I get less pain on Brufen than on Clinoril because of a difference in the drugs, the fact that I had a couple of late nights and drank a little alcohol, because I skimped yoga or because winter is coming? It would take at least two seasons to be sure. I always try to give my therapies a fair trial - probably far beyond the point where a streetwise person would give up.

And, in this sense, I was naive: I had never been interested in recreational drugs and had only once or twice shared a puff of a joint to be companionable and once smoked a little hashish in a water-pipe that friends made for me out of a Vegemite jar and a curl of glass tube because they did not want me to be the gooseberry. My only responses to marihuana and hashish have been slight loss of peripheral vision and an irksome sense that time was passing too slowly.

Five or six years before I was prescribed Ativan, when I casually mentioned that I had been prescribed Valium for asthma and found it totally useless, Udo joyfully offered to buy my scrips. I was quite

bemused and irritated because I found the suggestion silly. Although he described a kind of euphoria from the drug, it had had no effect on me at all. I could not imagine what he was enthusing about. Later, I heard that he did, in fact, become addicted, having as much difficulty with Valium as I later had with Ativan.

I did not associate the two drugs until I was far gone in withdrawal.

Of course, anyone who read a daily paper knew that Valium was addictive and I even had vague memories of Miltown but I had mistakenly thought that government could be trusted to stop that sort of thing as soon as the information became public.

The fact that I had taken both Librium and Valium before and had had no difficulty giving them up made me dangerously complacent. I did not know that they were related to each other and to Ativan. And I did not know - what most doctors still do not know in any useful way - that the benzodiazepines are a large family of drugs and that the short-acting drugs are far more virulent than the long-acting.

Believing – wrongly - that some people were more likely to become addicted than others, I prided myself on not being an addictive personality, not knowing that I had not escaped because of my great willpower and strength of mind but because Valium and Librium are long-acting and I had been on them for short periods of time.

When Vince tried to tell me that Ativan was dangerous, referring to the commonplaces about Valium, I arrogantly told him that Valium was diazepam whereas Ativan was lorazepam. Sorry, Vincenzo: you were right and I was foolishly wrong.

I quite soon found out that personalities are not addictive - drugs are. An ingenious test of problem solving among rats showed that benzodiazepines did not effect their capacity to perform the component steps of a task but did impair overall performance, suggesting that 'certain of the apparent anti-anxiety effects of benzodiazepines may in fact be due to impaired decision-making caused by misjudgment of the significance of sensory input.'<sup>3</sup>

This obscure experiment supports all those therapists who resist the use of these tranquillisers for fear of diminishing the patient's normal capacity to respond. For myself, the longer I took Ativan, the less I was able to put two and two together and make addiction.

My first experience of Ativan was so blissful that I had no reason to expect anything but good from it. Without knowledge of tolerance, addiction sickness, rebound and withdrawal, I had no frame of reference to help me interpret my unfolding experience. When I became overwhelmingly distressed, I reasoned that I had not changed my medication, so I must explain my symptoms by looking for changes in my body or my life.

I did not have far to look, since writing is the second worst paid activity after fruit-picking and, after fire-fighting, the second most stressful. And I was not cut out to be a corporation wife. Probably I was not cut out to be a mother.

Eventually I would learn that Valium was only one of several hundred benzodiazepines of which about fifty have been approved for sale. Ativan, a short-acting formulation that for several months had seemed like a miracle drug to me, was in fact related to Valium and much worse than its long-acting congene.

And the Federal government was in an ambiguous position. Recognising the addiction problem, it made certain tranquillisers, not normally available on NHS prescription, available to addicted patients in government-funded nursing homes if they had been on the drugs for six months and a withdrawal attempt had failed.

Is there a story behind this? The summary of the basis for Ativan's approval by the FDA notes 'sporadic convulsions were observed during the overnight food withdrawal period in the treated rats.' Could it be that patients deprived of control over their pills when they entered the homes had been going into flamboyant convulsions? And were these such that the most optimistic doctor could not explain them away as a symptom of the condition for which the drugs had originally been prescribed?

Anyway, recognising addiction in the NHS was not accompanied by any attempt to schedule the drugs as addictive nor any systematic, large-scale attempt to educate either prescribing doctors or the public despite the fact that the aging brain is extremely susceptible and that most elderly victims cannot be withdrawn.

The similarity between BZD side effects and the memory deficits of dementia, including Alzheimer's Disease, have often been noted in medical literature yet gerontologists have been slow to question whether their patients' symptoms are genuine signs of senility or

artifacts of their addiction. However, there seems to be consensus among nurses and pharmacologists that benzodiazepines manufacture senility.

Despite the 1984 WHO decision to schedule BZDs as drugs of addiction, responses to this vast, expensive and grave problem are piecemeal and inconsistent at both state and federal levels, and worldwide.

Journals like MIMS, which publish only as much information as the pharmaceutical manufacturers can be compelled to release, reveal an evolution of warnings on the benzodiazepines as subtle as the changing shape of the coke bottle but where Coca Cola adapts joyfully and imaginatively to changing fashions and lifestyles, the drug companies reveal nothing unless they are forced to by government regulation or public clamour - and even then, the information is framed in the way least damaging to sales.

In 1961 the drug houses recognised addiction with doses higher than normal and five years later they acknowledged addiction on normal doses. By 1982, Roche (UK) said that the typical Valium addict would be a drug or alcohol abuser. In 1986 Australian Roche warned that addiction could occur with excessive doses.

There are geographical differences in the time lag on warnings: Australian data sheets took ten years to mention that the drugs should only be prescribed for short periods and to admit that tolerance occurred; British data sheets say the maximum prescription should be four weeks while the Australian ones do not fix a limit.<sup>5</sup>

I particularly savored the irony of Precautions (7) and (8) in the *National Drug Information Service Profile* (US) entry on lorazepam (Ativan) for 1982:

(7) Dependence: Physical and psychological dependence have rarely been reported at recommended doses of benzodiazepines. However caution should be exercised in prescribing for individuals known to be addiction-prone or for those whose histories suggest they may increase the dose on their own initiative. (8) Abrupt Withdrawal: Patients who have been on benzodiazepines for some time, particularly at high dosage, should not have the treatment terminated abruptly as this has resulted in withdrawal symptoms including convulsions, tremor, abdominal and muscle cramps, vomiting, sweating, nervousness and insomnia.

Precaution (9) repeats the advice against abrupt termination in relation to epileptics and suggests an increase in anticonvulsant medication to avoid an increase in the frequency and/or severity of grand mal seizures while on BZD therapy.

The reference to 'addiction-prone' individuals is a way of blaming the victim: very few benzo junkies are alcoholics, smokers, or users of recreational drugs - although the response to benzodiazepines probably varies according to alcohol intake. BZD users certainly tend to drink less alcohol. The subtext of the NDIS message is that the drugs are addictive, but if the doctor is careful to withdraw the patient slowly, s/he will never know. And people who don't know, won't sue.

The facts that emerged from my investigation took me rather beyond the problem of iatragenic drug addiction to the modem practice of medicine and the obsolescent concept of healing. My first political involvement with doctors began in the 1960s, with campaigns to have the prohibition on abortion lifted together with the accessory prohibitions on advertising and display of contraception and on frank references to sex.

By 1963, I had decided that, while individual doctors could be compassionate and thoughtful, the medical profession as a whole suffered from a sort of moral cretinism. Their conduct was more guided by superstition and self-interest than science.

The general public and its legislators treat doctors with more respect than they deserve because, although very few doctors are medical scientists, naivety about science allows them to claim authority that should only derive from science proper. 'Doctors' are not 'medical scientists'. Part of the problem with benzodiazepine addiction is that patients respect their doctors too much and doctors respect their patients too little.

My view of the benzodiazepine issue, shaped by my knowledge of abortion, contraception and women's health, rapidly broadened into a discussion of the alliance between doctors and drug houses - the medical-industrial complex. This book is by no means simply a response to my personal benzo defeat.

Although WHO favors the word 'dependency', <sup>6</sup> I shall use the word 'addiction'. There is an important issue of moral agency here: if I am *dependent* on a drug, that is my responsibility and possibly my fault; if I am *addicted* to a drug, that is the drug's fault and the responsibility of

the doctor who prescribed it and the company that manufactured it and the government that failed to regulate it. Superficially, 'dependency' might appear more compassionate and less judgmental than 'addiction' in relation to pharmaceutical drug use. Fundamentally, it is another way of shifting responsibility from the medical-industrial complex to the consumers - blaming the victim.

Confusion about moral agency has led to immense waste of public money on anti-drug-abuse campaigns that have no hope of success and the criminalising of what is a medical problem even when the drugs involved are legally prohibited.

Benzodiazepine addiction is many times more common than heroin addiction and withdrawal is more cruel, yet benzodiazepines receive barely a mention in anti-drug-abuse pamphlets directed at the general public and are only entering mainstream public debate after new prescriptions for them have begun to decline with infinite slowness. The main moral and social difference between benzos and heroin is that doctors, drug companies and tax collectors profit from benzos.

I did not go to the doctor to become a drug addict. No one does. This book will have achieved its minimum purpose if the benzodiazepine family of drugs is scheduled with drugs of addiction for limited short-term use, if the medical profession undertakes more responsible prescribing habits and if health consumers are inspired to stand up for their rights against the medical-industrial complex.

However, benzodiazepines are only one scandal in the broad history of rogue drugs. Thalidomide is a household word but the thoroughly documented history of many other profitable destructive drugs is not well known. The general public does not expect to be sold lethal drugs as medicines any more than it expects to buy lethal motorcars. Buyers and consumers tend to believe that a hygiene factor like safety can be taken for granted. Only the well educated and the street-wise know that it cannot.

The scandals point up a pattern in health care delivery. Health, in the form of drugs and services that are meant to enhance or restore it, is seen as a profitable commodity. Primary care, the preventive services that preserve existing health, is neglected. Although primary care maintains a good few individuals in service jobs, it is considerably less expensive and more cost-beneficial than the commodity market in health.

So far, rogue drugs have called up public agitation and litigation on a case-by-case basis. Now it is time to accept that rogue drugs are not random misfortunes but endemic to the medical-industrial complex. Government, taxpayers, consumers and doctors of goodwill must effect a shift from private profit in health care to public savings. The savings, of course, include more the tax dollar. They include human life, health and dignity.

## CHAPTER 3 ROGUE DRUGS

The rats showed mild chronic convulsions.

Clinical Review of NDA 17,794: Ativan.

Ask a member of the general public to name a rogue drug and the chances are that if they do not name thalidomide, they will choose Valium. These drugs have become household words but they are by no means the only rogues in the history of pharmaceuticals; nor even the most destructive; nor the most scandalous. Nor are they lone aberrations. They fit into a general pattern of corporate crime in the pharmaceutical industry, alongside Clioquinol, Oraflex, Selacryn, DES, and many other rogue drugs. To these we must add the Dalkon Shield, the Jarvik heart and DOW's silicone breast implant - not drugs, admittedly, but devices marketed by large corporations to the unsuspecting public via medical middlemen. To make sense of the tragedies caused by drugs that kill the liver, cause cancer, deform the unborn and addict the brain, we need to place them in the context of pharmaceutical marketing.

I shall not be presenting any new information: all of these stories are public domain and most of them have already been critically analysed by investigative journalists, public interest groups and academics. What I hope to do is to demonstrate a connective pattern between events that have been treated as isolated scandals of capitalism, to be discussed for nine days and then forgotten - except by the survivors.

Most of the material is American - not because American drug companies are uniquely criminal but because they are well documented. Names like Ciba-Geigy (Swiss), Grunenthal (German), and Distillers (British) will remind readers that rogue drugs may appear anywhere. Let me begin my survey with the potted history of a preparation, less familiar than thalidomide or Valium, that has more visible features of corporate crime.

Most people know about cholesterol. Not everyone knows that the body produces its own. Thus, when reports of a statistical link between high cholesterol and heart disease began to appear in the 1950s, American manufacturers concluded that many people would prefer a

quick pharmaceutical fix for endogenous cholesterol over a punishing diet for the sort we eat.

The industry identified a billion-dollar market comprised of millions of middle-aged Americans requiring lifetime therapy with an anticholesterol agent. William S. Merrell beat its competitors to the cash register with a specially developed drug simply called MER/29 (triparanol). It was launched in March 1960 with heavy promotion and systematically misleading advertising. Within months of its release, reports came in of hair loss, dry, scaly skin, watery eyes, blurred vision, cataracts and eventual blindness. These reports echoed existing observations from Merrell's own animal trials, which recorded, in addition, severe liver damage and death.

The criminal history of Mer/29 began with registration attempts in the late 1950s. Cover-up of disaster in the laboratory and in clinical trials was followed by persistent manipulation of evidence, fraudulent submissions to the FDA, and refusal of samples to independent testers who might identify and publish the all too obvious risks. When competitors did identify adverse reactions, they were explained away. The need for secrecy conflicted with the need for market softening. When Dr. Wong, of Washington, requested samples for some Pentagon generals, his request was denied because Merrell hesitated 'to use any new drug on those valuable people.' They noted, however, that Dr. Wong had other patients, including 'negro hospital patients.'

Early in 1962, the fraud was revealed by an accident that gave the FDA an advantage in its long-standing surveillance of Merrell. The FDA acquired enough evidence to have the drug recalled and to initiate legal action. Ninety-five per cent of MER/29 tort cases were settled between 1962 and 1967. In 1963, a Federal Grand jury handed down a twelve-count indictment against Merrell, its parent company, Richardson-Merrell, and three of its employees. In keeping with the general reluctance to imprison white-collar criminals, the three individuals received probation. The company, which in 1960 had anticipated a \$4.25 billion income from MER/29, received a small fine.

It was 1966, four years after MER/29 had been withdrawn, when Dr. James Goddard, then head of the FDA, gave a speech to the Pharmaceutical Manufacturers Association, based in Washington. He observed that MER/29 was not an isolated case:

Gentlemen, we must keep our eyes on the patient. For - once you get through the medical reports and the counselor's opinions, the advertising and the marketing data, the licensing and distribution agreements, the protocols and letters of credit, the labeling and packaging, and the reports by the company treasurer - once you get through all that, you reach the physician who will administer your product to a human being. At the end of that long line is a human life. Some of you have forgotten that basic fact.<sup>2</sup>

Evidence about drugs is accumulated during laboratory studies on animals ranging from rats to monkeys, then in small-scale clinical studies on people whose dire need for treatment counterbalances the risks of a new drug. If these trials yield positive responses and no great hazards, trials on larger human populations will follow. The results produced by this sequence are rarely adequate for complete safety. A great deal more evidence becomes available after the drug reaches the market, when the real life risks appear.

In other words, anyone talking a newly released drug is an unwitting guinea pig although doctors, who enthusiastically offer a new drug, do not feel obliged to ask their patients for consent to participate in its real-life trial. This final test is often the only way to identify a rogue drug when the early phases of research have been perverted by corporate crime.

Covering up the death of a laboratory monkey is easy: covering up the death of a human is somewhat harder.

Professor Mickey C. Smith, former marketing manager for a pharmaceutical firm and author of *Principles of Pharmaceutical Marketing* tells us that the curve of acceptance for a new drug is very like the life cycle of any new product.<sup>3</sup>

The implications of this statement are startling. Most drugs are not marketed directly to the general public but to prescribing doctors and dispensing pharmacists. They are only advertised in professional journals and their packaging is restrained and functional.

Surely the life cycle of drugs is subject to some sort of scientific law of problem solving and safety testing rather than to market swings? Are drugs that can maim and kill really just like frisbees and paddle-pops?

Dutton analysed four United States health scandals in both comprehensive and minute detail: DES, the swine flu vaccination campaign of 1976, the Jarvik artificial heart and the unresolved controversy over genetic engineering. After distinguishing between

tragedies caused by deficiencies in the state of knowledge at the time and scandals deriving from characteristic flaws in decision-making, she went on to identify seven such flaws:

- 1. Technological optimism: the tendency of providers who might be drug houses, doctors or bureaucrats to inflate the dangers of not having an innovation and to inflate the benefits of having it.
- 2. Underestimating the risks of the innovation itself. 'No evidence of risks was taken as evidence of no risks.'
- 3. Suppression of doubt and dissent: false unanimity based on only the positive side of what was in fact a clearly drawn controversy.
- 4. Valuing hard data more than soft concerns: for example, the allegedly proven physical benefit compared with vaguely suspected physical or ethical harm.
- 5. Fragmentary or tunnel vision analysis of problems without regard to the social context in which they occur or in which the solutions must be applied.
- 6. Assumption of unlimited resources: an assumption that was frequently proven unrealistic.
- 7. The inflexibility of decisions once they were made.<sup>4</sup>

This list is certainly justified from the evidence Dutton presents and the evidence presented justifies the author's well-argued concern to introduce more public discussion and accountability in health matters. There are, however, certain legal constraints on what may be sold in the name of health.

Dr. Dutton is aware, for example, of culpable lapses in the conduct of the FDA when evidence emerged that DES was valueless and carcinogenic and she notes cynicism in the marketing policies of major drug houses. Such breaches of laws, regulations and protocols established to protect the public go beyond flaws in decision-making. They are calculated flouting of lawful decision-making processes. Society made an effort to facilitate decision-making and the providers rejected its rules.

Dutton's list is incomplete without some consideration of deliberate wrongdoing. There is more to white-collar crime than optimism.

The main point to notice in Professor Smith's account is that drugs are overvalued on introduction and misused in the first phase of the life cycle - substantially because they are poorly tested, the evidence about unwanted effects is incomplete, suppressed or manipulated, and marketing is misleadingly positive.

Despite the alert observations and prompt complaints of a few idealistic doctors, the medical profession as a whole accepts the drug industry's propaganda, maintaining itself in cheerful ignorance, frustrating attempts to monitor unwanted effects, and retarding the recall of rogue drugs.

The move to the second phase of the life cycle, when problems are discovered and the drugs are devalued and condemned, is not simply a whimsical change in the product life-cycle due to vagaries of consumer taste. Valium does not replace barbiturates as skateboards replace frisbees, merely because of an arbitrary change in fashion. The rejection flows from the discovery of unwanted effects with often catastrophic results for the human guinea pigs. This precipitates further, usually more thorough, independent research and the collection of wide-scale epidemiological data from the public - some of whom have already paid with their lives, their livelihoods and the health of their children.

Occasionally a community reckons its costs. In 1974, Senator Edward Kennedy chaired a Subcommittee on Health that reported the medical and hospital costs of adverse drug reactions (ADRS) in the USA each year at two billion dollars in medical and hospital costs and 30,000 deaths. Eighty per cent of adverse drug reactions were thought to be preventable. Others estimate ADR hospital admissions at one million per annum and deaths at over 130,000 per annum for hospital ADRs alone.<sup>5</sup>

Once the risks are identified, the loved ones buried - or guide-dogs or wheelchairs bought, and the law suits settled, the drugs are either withdrawn from sale or life cycle stage three emerges with the realistic evaluation of their comparative worth. Doctors and manufacturers accept this cycle as normal and inevitable - much as the medievals accepted war, pestilence and famine. It is neither normal nor inevitable.

The discrepancy between the actual use of various drugs and their putative appropriate use is caused substantially by advertising, promotion, and public relations. In other words, neither commonsense not science can ensure that a drug developed for amoebic dysentery will be used for amoebic dysentery. With skilful marketing, it could be used for all forms of dysentery, or flu, and ingrown toenails.

A sedative tested for masturbation anxiety in male adolescents might be given to pregnant women for morning sickness and one that has proven itself excellent for taming a lynx might be prescribed to help a female virgin cope with university. The harms that arise from these decisions are predictable and thus avoidable consequences.

### **CLIOQUINOL**

Clioquinol rivals the benzodiazepines as the rogue drug with the longest survival on the modem market. In 1934 Ciba (now Ciba-Geigy) marketed clioquinol for amoebic dysentery, later extending its indications to include all dysentery and licensing other multinationals to produce it. The drug remained in use for thirty-five years. It was often marketed for travellers' diarrhoea under the name Entero-Vioform.

When the drug entered the Japanese market in 1953, it was spectacularly successful. Its sales rose from 38.4 kg in 1953 to 8448 kg in 1962. Clioquinol was particularly valued because the Japanese place special cultural emphasis on the wellbeing of the stomach - similar, perhaps to the American preoccupation with cholesterol or straight teeth.

Ciba promoted the drug for use in general abdominal trouble without limiting the dosage or length of treatment; hence the Japanese were using it not only to treat but to prevent dysentery and also as a digestive stabilizer - like a tonic for the intestinal tract.

The first symptoms were vague and difficult to diagnose: numbness and tingling in the feet leading to total loss of sensation and eventually paralysis of the feet and legs, muscle weakness, and bladder disturbance. Some victims succumbed to diarrhoea and severe abdominal pain, epileptic convulsions and death. Others suffered disturbed vision and eventual blindness, giving the syndrome its name subacute myelo-optic neuropathy or SMON for short.<sup>6</sup>

At first, the mystery disease was treated as a virus and the patients were isolated. It was only attributed to clioquinol in 1970, when observations concerning green tongues and greenish urine gave a clue to several Japanese researchers who then correlated size of dose, length of treatment and intensity of symptoms. Following these studies, the Japanese government banned the drug - despite objections from Ciba-Geigy. Japan reported the highest number of cases (10,000) but SMON was also reported in Sweden, Norway, Denmark, the iN The

Netherlands, France, West Germany, Indonesia, Switzerland, Australia, and India with a few cases from the US, and elsewhere. In 1981, when Ciba had settled the bulk of the Japanese law suits, the payments totaled \$490 million - thought at the time to be the largest restitution ever made.

#### THE DALKON SHIELD

The Dalkon Shield surpasses even MER/29 for irregularities in its research and development, licensing and marketing. The small, flat intra-uterine contraceptive device was devised in the mid 1960s by entrepreneurs who sold it for manufacture to A. H. Robins, of Richmond, Virginia. It was less efficient than other devices in preventing conception but more efficient at causing abortion in foetuses conceived.

In the US, about 110,000 women conceived with the Shield in place; probably 66,000 of these pregnancies aborted with haemorrhage and infection. Hundreds of Dalkon babies were born premature, with birth defects including blindness, cerebral palsy, and mental retardation. No fewer than eighteen American women died of Shield-induced pelvic inflammatory disease (PID). Many others bought their lives at the cost of total hysterectomy. For some of these women, their first pregnancy was their last. Seven thousand of the 100,000 to 160,000 Shields that reached Australia caused sufficiently gross side effects to justify litigation. We can only guess the total number of women harmed but unwilling to go to law or unable to afford legal help.

The three inventors sold the cockroach-shaped device to Robins on the basis of fraudulent claims as to its efficacy and safety. Robins knew the truth, but chose to ignore it, telling salesmen to fudge the copper content of the device and to say that its components were confidential.

Reanalysis of raw data showed that the actual rate of infection was from fifteen to twenty times higher than the reported 0.6 per cent. Some information was simply concealed. Robins' own salesmen reported the pregnancies, abortions and maternal deaths to the company during (northern) Summer 1972. A trial doctor, Dr. Thad Earl, who personally observed half-a-dozen pregnancies and septic abortions, also reported similar nationwide findings. He advised early removal of the device in pregnancy, as did other doctors. Robins did little for eighteen months. The Planned Parenthood Federation reported 26.4 per cent difficulties in their clinics.

In May 1974, two years after Earl's original warning, Robins sent out a 'Dear Dr.' letter advising therapeutic abortion in case of pregnancy. Although the FDA requested suspension of sales, Robins did not advise removal of the remaining shields until 1980, when law suits were mounting. By 1988, there had been 5,000 suits and 6,900 out of court settlements.

Australia had the highest number of complainants outside the USA. Peter Cashman, a Sydney lawyer who handled many of the Australian cases, concluded that 'the Dalkon Shield has now become the most litigated product in history.'<sup>10</sup>

The Dalkon atrocity is unique among these histories, because there is no doubt that the designing and marketing of the product was a calculated risk from start to finish. The entrepreneurs did the calculations - the patients ran the risk.

The first designer/manufacturers had legal advice about how to describe the product in order to incur less restrictive testing and lawyers became parties to subsequent cover-ups. Robins both paid expert witnesses who testified at hearings on the device and refused funding for independent research. The case reveals systematic, calculated deception that cannot easily be excused as the result of technological optimism, human error or of difficulty in assigning responsibility within a corporate structure.

The case had ramifications beyond the harm done to individual women and their families. The name 'Dalkon Shield' became synonymous with 'intra-uterine device' and women rejected the IUD as a method of contraception even though other designs were generally safe and effective. Government regulating agencies increased the criteria of safety to exclude devices with formerly acceptable records.

Data from the Family Planning Clinic of NSW show that total IUD insertions fell from 2,009 in 1984-85 to 920 in 1985-86. The percentage of new patients choosing IUDs in that time fell from 8 per cent to 5.5 per cent. In the USA, Searle withdrew the Gravigard from sale because of the cost of legal cases - even though it was winning in the courts. Other firms withdrew their IUDs until only one remained on sale. It is predicted that more than eighty thousand abortions will occur due to the unavailability of IUDs in the USA.<sup>11</sup>

#### **DES**

DES, the first laboratory-made oestrogen, was synthesized in 1938 but not immediately patented. Eventually, uses were found for the preparation. By 1941, the FDA had approved it as a lactation suppressant, for use in prostatic cancer, and for hormone replacement therapy (HRT). In 1947 Eli Lilly, the major producer of DES, marketed it to prevent miscarriage - despite evidence of its involvement in cancer and lack of evidence of efficacy in miscarriage. From time to time, it was touted as a general prophylactic for pregnancy and also as a morning-after abortifacient.

In other words, the substance was not developed to cure a disease but diseases were found to justify the marketing of an available substance.

The function of the substance was unknown and scientists immediately noticed that the rationales for all the various uses were inconsistent; nevertheless, it sold well. Between 1932 and 1947, over twenty-four articles identified oestrogen and DES as carcinogens. By 1952, four convincing studies had shown no efficacy in preventing miscarriage and Dr. William Dieckmann's meticulous double blind study showed no therapeutic value in pregnancy but increases in miscarriages, neonatal deaths and premature births. Eventually, it was discovered that twelve days' use at three months gestation was enough to cause cervical cancer in female offspring at adulthood. This discovery occurred during the real life testing of the drug.

Early in the 1980s, structural anomalies of the cervix and vagina were discovered in 25-50 per cent of DES daughters, compared with 2 per cent of controls, and the girls were twice as likely to have dysphasia and carcinoma in situ of the cervix or vagina. DES daughters also had abnormalities of the upper tract such as constricted uterus, narrow cervical canal, and misshapen tubes.

They had substantially higher risk than other women for difficulty becoming pregnant, miscarriage, stillbirth, ectopic pregnancy, and premature delivery. Male children had testicular abnormalities and fertility problems. DES mothers also had substantially increased breast and other hormone-related cancers.<sup>12</sup>

The drug was not withdrawn from medical uses until 1972, leaving behind a profoundly interesting scientific mystery for oncologists and embryologists: transplacental carcinogenesis. How could a drug given to a pregnant women cause cancer across the placental barrier?

The girl who made medico-legal history by bringing the first successful action against DES had lost both womb and vagina at the age of eighteen. When 6,000 plaintiffs in forty American states sued various companies, some of them received awards exceeding one million dollars. Beginning in 1974, DES Action groups have worked hard to educate the public and get laws passed on DES, both for the control of the drug and the follow-up and screening of victims.

However, DES was still available as one of ten hormones used to fatten poultry and livestock quickly and with savings in feed before they were killed. Farm lobbyists defended the drug when it was found that scraps from DES-fattened chickens sold as food for ranch minks rendered the females sterile and chicken necks eaten by kitchen workers caponised the men.

There is also a strong suspicion that premature sexual development among girls and boys in Puerto Rico during the mid 1980s was due to unlawful use of DES in livestock.

#### **ORAFLEX**

'And from the firm that brought you DES, we have Oraflex - another great Eli Lilly product!' Marketing and testing practices that are conducive to one disaster will, if uncorrected, be conducive to more than one. Benoxaprofen is the generic name for the anti-arthritis drug that was briefly marketed as Oraflex in the US and Orpren in the UK. Released outside America in October 1980, it caused at least ninety-six deaths. The typical victim might have been a 61-year-old arthritic: she died on 600mg daily - in great pain, vomiting blood, with kidney failure followed by a heart attack and death.<sup>13</sup>

Under all its names, the drug caused separation of fingernails, hives, heartburn, stomach pain, diarrhoea, breathing problems, phototoxicity, gastrointestinal haemorrhage, jaundice, liver failure, kidney failure and death. Pressure for action against the product intensified in late July 1982 and the British government suspended sales of Orpren in August. Lilly voluntarily withdrew Oraflex from the United States market as a better public relations move than waiting for official instructions to recall it.

While the FDA rejected a recommendation to prosecute Lilly in 1982, more than 100 negligence suits were eventually brought. The Reagan government's stated policy was to avoid an adversarial relationship with the pharmaceutical industry.

# **SELACRYN**

Smithkline's Selacryn was a blood pressure treatment that could destroy 98 per cent of the liver in a healthy 34-year-old female in less than five months. The drug, generically called tichrynafen, caused no fewer than sixty deaths and five hundred and thirteen cases of liver damage in 265,000 US users. The majority of these tragedies would have been preventable had Smithkline followed FDA reporting regulations.<sup>15</sup>

Clinical trials, which began in 1976, produced 8 liver cases in 533 patients. These results were treated as accidental. The FDA accepted the evidence of these 533 cases, although the normal trial sample is 700 to 1500. Considering that Selacryn was sold for long-term use on millions of people, this sample was too low. Clinical testing on several thousand people would have uncovered liver damage before the drug was marketed instead of after. New Drug Applications (NDA) normally averaged two years processing in the FDA but Selacryn's application took eighteen months to clear. Smithkline referred to only one case of liver damage and the FDA noted the other eight but considered them 'minimal and trivial'.

The company received permission to sell on condition that they included a warning of report damage but the published warning claimed that no causal connection had been established. Many doctors must have read this ambiguous statement as a green light for Selacryn because the drug was an immediate success.

Disaster was immediately apparent. Within days of Selacryn's release, patients shifted from thiazide to the new rival experienced kidney shutdown due to the sudden switch from heightened uric acid to lowered - a response that had also been reported from Europe. Reports of liver damage continued during 1979.<sup>16</sup>

Prosecutors later revealed that in March 1979, Anphar Rolland, the French firm that licensed Smithkline to sell tichrynafen, notified them of thirteen cases of liver disorder including five that were probably drug

related; in June a further twenty cases were reported, including six shown to be definitely drug related.

Smithkline was fined \$100,000 and three of its executives were put on probation and sentenced to two hundred hours of community service. Some observers felt that this was a light sentence for unjustifiable homicide.

#### **THALIDOMIDE**

The little girl scooted merrily across the nursery floor to get her potty. Balancing on tiny flippers, she held it to her belly with stumps of arms ending in stubs of fingers: she had no legs and her urino-genital systems opened beneath her navel. Otherwise she was quite normal. Or was she? The staff of the Pestolozzi Homes for Thalidomide Victims had been too compassionate to investigate whether her visceral tracts were as deformed as her external genitalia. Everyone now knows that thalidomide caused babies to be born without arms and/or legs. Only their doctors, nurses and parents know the full extent and variety of abnormalities caused by the drug.

During the 1950s and 1960s, eight thousand thalidomide babies were recorded but probably twice as many died at birth and four times as many miscarried.

The degree of deformity depended on the stage of pregnancy when the drug was taken and the dosage: deformed limbs or none, deformed genitals, bowels, faces, and ears, blindness, mental retardation, and projectile vomiting. Of twelve hundred babies born in England (where the drug was called Distaval) about two-thirds died of massive haemorrhaging at birth.<sup>17</sup>

Originally marketed by the German firm Chemie Grunenthal as Contergan, a non-toxic tranquilizer, early tests showed that the drug was worthless as a sedative and caused nervous disturbances. It was also known to have an antihyperthyroid effect that was associated with birth defects. By 1961, it was impossible to deny claims that it caused peripheral neuritis and Grunenthal's own staff doctor said that he would not prescribe it.

Meanwhile, doctors in Germany were frantically trying to identify the cause of an outbreak of phocomelia - a rare birth defect in which rudimentary flipper-like fingers appear in place of a normal limb: in eight West German paediatric clinics, no cases at all were recorded between 1954 and 1959 but twelve occurred in 1959, rising to eighty-three in 1960 and three hundred and two a year later. The epidemic was worse than textbook cases where only one limb was affected -doctors were now finding that any or all limbs could be deformed.

In the US, Richardson-Merrell energetically sought FDA approval and was held up by Dr. Frances Kelsey who was - along with Dr. Hubert Giggleberger and Dr. Helen Taussig - one of few heroes in this story. Dr. Kelsey delayed Merrell's application from September 1961 because thalidomide did not behave like chemically similar drugs. Fifteen years earlier, she had herself shown a connection between the potential to cause peripheral neuritis and teratogeneity - the capacity to cause foetal deformity.<sup>18</sup>

During this hiatus, phocomelia was reported from Germany. Merrell immediately withdraw its application but the drug itself was not withdrawn worldwide till 1985. In Germany, the manufacturing company was indicted for intent to commit bodily harm and involuntary manslaughter. Eventually the charges were dropped and Grunenthal agreed to pay German child victims \$31 million.

# **MINOR TRANQUILLISERS**

The so-called 'minor' tranquilizers are not named after qualities of the drugs themselves but of the conditions for which they are indicated. Drugs like chlorpromazine and fluphenazine are used for major psychoses such as schizophrenia while meprobamate and chlordiazepoxide are used for minor conditions such as sleeplessness and anxiety. Hence the latter pair, better known as Miltown and Librium, are called *minor* tranquilizers - an accident of medical nomenclature that may have encouraged doctors to prescribe them recklessly. As with most rogue drugs, major problems emerged early in their life cycle.

Most of the minor tranquilizers are general in their effect so that although is common to distinguish between *anxiolytics* that act as *sedatives* for anxiety and *hypnotics* to encourage sleep, all hypnotics have anxiolytic properties but only at a cost of sleepiness, lethargy, impaired mental activity and co-ordination. The terms 'anxiolytic', 'sedative', and 'hypnotic' are not precise descriptors of drugs themselves but of the uses to which they are put.

Librium, the first benzodiazepine, was the first drug in which anxiolytic properties were considerably greater than hypnotic effects. However, it was not the first minor tranquilliser.

Miltown occupies that place.<sup>19</sup> It was developed from the serendipitous discovery in 1940 of a muscle relaxant, mephenesin, during a quest for an antibacterial agent by the British Drug House in London. Like DES, the substance was not developed to cure a disease but diseases were found to justify the marketing of a developed substance. The original preparation caused unwanted effects on the metabolism that took eleven years' research to eliminate.<sup>20</sup>

One of first and most glowing reports on the new drug appeared in *Cosmopolitan* during 1955: 'Safe and quick, Miltown does not deaden or dull the senses, and is not habit forming. It relaxes the muscles, calms the mind, and gives people a renewed ability to enjoy life.'

Case studies reported that it improved sleep, relieving blues, stomach distress, neurodermatitis, and even excessive perspiration.<sup>21</sup> By 1958, the drug was an international success. The Japanese were reported to be wild for 'tranki', mainly meprobamate, which rivaled Alka Seltzer on hoardings and in newspapers.<sup>22</sup> In the same year, a prison study showed meprobamate to be not habit forming.<sup>23</sup>

Meprobamate replaced the notorious barbiturate family as a safer way to sleep - safer, but not quite safe. It produces torpor, drowsiness, and oversedation; also rashes, purpura, oedema, fever and liver induction; it is dangerous in overdose. It can also readily cause an acute confusional state (delirium) in the elderly. Not only was it found to cause addiction, but to be useless as a sedative. After many years of use, double-blind tests showed it was no more effective than placebo in the doses usually prescribed.

Yet, as late as 1983, some still advocated it for anxiety with excessive muscular tension.<sup>24</sup> Perhaps the drug survived because, alone of the rogue drugs, it did not attract lawsuits. The end fate of Miltown was to be an exemplar of successful marketing.

Miltown did not lose its market niche simply because it had been discredited. It was being crowded out by rivals - even though the years 1970-85 demonstrated that 'the medical use of hypnotics and anxiolytics for all but brief episodes readily produces dependence.'<sup>25</sup>

The long list of addictive drugs consists of individual preparations - chloral hydrate, chlormethiazole, ethchlorvynol, glutethimide, meprobamate, methyprylone, methaqualone and whole families of drugs - the antihistamines, the barbiturates and the benzodiazepines. The history of the last group represents the triumph of greed over experience.

### THE BENZODIAZEPINES

Librium first appeared in the headlines as the drug that tamed a lynx at the San Diego Zoo. Chlordiazepoxide (CDX) was discovered in 1957 at the Roche laboratories and immediately recognised for its behavioral effects on aggressive animals: it was sedative, a muscle relaxant, anticonvulsant, appetite stimulating, non-toxic, non-teratogenic in rats and dogs, and apparently quelled fear.

The first clinical reports, in 1959, suggested that it was valuable for nonpsychotic anxiety but unhelpful for psychosis. It seemed helpful in dermatological disorders associated with anxiety.<sup>26</sup>

This discovery began the still active practice of using BZD for all disorders with an alleged stress component even though its efficacy is largely theoretical and its muscle relaxant properties make it patently unsuitable for such conditions as asthma, arthritis and broken bones.

There were also reports of oversedation, drowsiness, somnolence, disarthia, ataxia, and weight-gain. The ten-fold increase in driving accidents reported in one study may have derived directly from drowsiness but there may also have been an indirect influence from another unwanted effect - heightened or disinhibited aggression. Despite all this, the results were deemed to justify widespread clinical trials. Early research was suggestive rather than conclusive, requiring more studies to clarify certain issues. In particular, the problem of benzodiazepine effect on driving was thought significant enough to invite more attention.<sup>27</sup>

Valium (diazepam), the second member to be added to the family, was also devised at Roche. It appeared in 1959, but was not released by the FDA until 1963. Although it was as toxic as CDX, it was a more effective muscle relaxant and anticonvulsant. The family expanded rapidly: Mogadon (nitrazepam) was released in Europe in 1965 followed by Dalmane (flurazepam) in the USA in 1970; then Nobrium (medazepam).

Roche had so many benzodiazepines that it did not patent them all but withheld some for release when first generation drugs had entered the declining phase of the life cycle. In 1961, Wyeth produced one drug, oxazepam that was marketed as Serax in the US from 1965. Although oxazepam was apparently less toxic than Librium and Valium, Wyeth's next discovery, lorazepam (Ativan) was considerably more potent.<sup>28</sup>

Despite the rudimentary state of knowledge in 1957-67, the market penetration of the benzodiazepines was truly phenomenal. This was partly due to advertising and promotion but the new family did have one considerable advantage: they were clearly more benign than barbiturates. In 1968-69 the Registrar General's Office, London, recorded 5,849 deaths due to drug ingestion but only sixteen of these cases were associated with BZD alone.

In 1974, a major textbook published by Drs. Greenblatt and Shader warned 'it is important that the apparent innocuousness of the benzodiazepines not lead to the assumption that [systematic epidemiologic] investigation is unnecessary.'<sup>29</sup> As with meprobamate, 'more benign than barbiturates' did not mean safe.

In 1960-61 almost one hundred studies were published, involving thousands of patients, with inadequate controls or none at all. Nevertheless, by 1967, 20.4 million prescriptions were written for minor tranquillisers in the USA - predominantly for BZD. This represented nearly thirty per cent of new scripts. Curiously, GPs wrote seventy-five per cent of these prescriptions while psychiatrists wrote only five per cent, suggesting that the drugs were already being used for blanket indications such as stress rather than for a precise diagnosis.

In the USA, chlordiazepoxide and diazepam were at, or near, the top of lists of most frequently used drugs, earning an estimated forty-two million dollars in 1968. Sales were also high in Great Britain and Australia; one hospital survey found similarly high usage across hospitals in the US, Canada, Israel and NZ. As tranquilliser use increased, so did public concern. The difficulty of doctors who had been trained to deal with objective pathology but were constantly faced with anxiety, grief or neurosis in practice was well recognised even then.

Most patients did not present with disease but dys-ease. Greenblatt and Shader had a warning for this also: `Although this is an appropriate target population, iatragenic overuse is always a potential problem.'<sup>30</sup> The release of suppressed anger under the influence of

benzodiazepines was reported but considered hard to measure, although it occurred frequently enough to be important.<sup>31</sup>

The drugs were known to be bad for respiratory disorders but this did not prevent their use for asthma in 1974<sup>32</sup> - and still did not in 1992. No gross reproductive influences were demonstrated in the early period but scientists recorded that BZD reaches fetuses rapidly and in excess concentration to the material amount. They suspected that it was probably responsible for lethargy, hypothermia, hypotonia, dangerously depressed breathing and other symptoms in newborn babies - especially if the mothers had taken very high doses.<sup>33</sup>

Suicidal depressions were reported, especially in the elderly.<sup>34</sup>

The last word on benzodiazepines in 1974 was that comments had to be tentative due to the difficulty of investigating adverse reactions.<sup>35</sup>

Ativan had already been implicated in car accident suits by 1970. From 1973, The Netherland's national association of physicians and pharmacists required warning stickers on drugs that might diminish driving skills and the scope of legal liability for car accidents attributable to BZD broadened in many jurisdictions during the 1980s.<sup>36</sup> But these changes occurred on the basis of commonsense, expedience and precedent - not on research.

Although both acute and chronic tolerance was reported from the earliest trials, information was deemed to be inconclusive.<sup>37</sup> Experiments on hospitalized patients suggested that withdrawal symptoms did occur and treatment should not be abruptly discontinued if the drugs had been taken for sixteen weeks or more.<sup>38</sup> Despite the early recognition of withdrawal symptoms, writers continued to focus on high dose and prolonged use attributing addiction at lower dose, shorter use to psychological dependence well into the 1980s.

The medical profession, happy to be relieved of crisis calls for barbiturate poisoning, prescribed benzodiazepines enthusiastically.

Concern for non-lethal effects passed mainly to feminists, nurses, and careers for the elderly. Between 1978 and 1982, Ruth Cooperstock of the Addiction Research Foundation in Toronto, explored the sexual politics of BZD, attempting to explain a worldwide phenomenon; twice as many women as men are prescribed benzodiazepines - and other psychotropic drugs.<sup>39</sup>

Eventually, the benzodiazepines would be divided into long- and short-acting types - roughly corresponding to first and second-generation drugs. Newer versions such as Ativan and Halcion, with a short half-life, were found to generate more severe withdrawal symptoms than those with a longer half-life, such as Valium and Librium.

Confusion arose when patients complained of short acting drugs and doctors pooh-poohed them on the basis of data from long-acting drugs. Marketers took advantage of the confusion to say that the drugs were non-addictive but the patients were neurotic.

By 1991, Dr. Graham Dukes, Professor of Drug Policy Science, University of Groningen wrote

It is incontrovertible that the benzodiazepines cause dependence ... Thirty years ago there was direct human experimental evidence of dependence; and although up to 1980 there was some excuse for believing that this was only a problem where unusually high doses were used, there had been accumulation of evidence from 1965 onwards that dependence could occur with entirely normal doses as well. By the end of the 1980's the phenomenon was thus entirely clear for the group of products as a whole and there was no reason to believe that any member of the family would be free of the problem.<sup>40</sup>

In the 1970s, financial considerations initiated the decline of BZD. Usage began to slow down in the US, UK and Australia due to government concern about the high cost to health budgets - added to increasing caution about side effects, pressure from the consumer health movement and the growth of alternative therapies. BZD litigation became more widespread in 1980s.

The Health Research Group of Ralph Nader's network, Public Citizen, published a short book entitled *Stopping Valium* in 1982, using the brand name as a generic for all benzodiazepines as 'biro' is used for all ballpoint pens and 'kleenex' for all paper tissues. The Group based its case for a ban on the general danger of addiction and the special dangers to pregnant women, the elderly and drivers.

Professor Smith's history of the minor tranquillisers, *Small Comfort* (1985) develops the idea that opposition to tranquillisers is an expression of pharmacological Calvinism or the moral belief that happiness should not be derived from pills. The discussion, based mainly on advertising and promotional material and public controversy, is remarkable mainly for what it does not say.

Professor Smith gives as much space to meprobomate as to the whole benzodiazepine family, minimizing addiction, and discussing only the most easily refuted criticisms in the briefest possible way. His book could be seen as the industry's response to an increasingly bad press and to Nader's book in particular.

The question of how far the success and survival of this family of drugs depended on wrongdoing is open at present. A yet more interesting question is why it took thirty years even to begin to persuade the medical profession that the drugs were not harmless. We find part of the answer in pharmaceutical marketing, part in corporate crime and part in the exigencies of modem medical practice.

#### **CORPORATE CRIME**

Pharmaceuticals, along with the car industry and oil and petrochemicals are the three most criminogenic industries in the USA.<sup>41</sup> Yet people generally think of 'crime' as street crime, not as something that can happen in laboratories and boardrooms.

Why is this? The obvious reason is that the media think that street crime will sell more papers while the public fined it more threatening. Police are very eager to feed journalists with crime stories but corporate wrongdoing requires investigative journalism of a high order and no one is particularly eager to feed investigative journalists.

Numerous criminologists allege that stereotypes of crime exclude the white-collar varieties because they are difficult to explain to the public. This is only partly true. The Australian public may not have understood the technical procedures that enabled bottom-of-the-harbor tax rackets to avoid the law, but it certainly understood that something stank. The broad concepts of profit and cover-up are accessible even when the precise evasive maneuvers remain obscure. People also understand limbless babies. As David Mason, father of a thalidomide child and leader of the parents group that negotiated the settlement with Distillers (UK) said, 'At the end of the clay, my daughter Louise still has no legs.'43

What the public cannot understand is how the governments they elect and pay for by their taxes can let this sort of thing happen.

The law itself contributes to the emphasis on street crime by failing to adapt to the more complex problems arising from corporate crime.

The criminal law was developed for individuals, drawing on concepts like *mens rea* or guilty intent that are not suited to corporations.

The Master Statements of Claim in the English group actions for benzodiazepine addiction against Wyeth and Roche repeatedly use the expressions 'Wyeth knew or should have known', 'knowledge Roche had or should have had', 'steps Wyeth should have taken by 1973', 'steps Roche should have taken after 1973'<sup>44</sup> - but who is Roche? Who is Wyeth? Could it have been that the individuals in the corporate structure who had the knowledge were not the individuals who decided to take steps? *Mens rea* does not seem to fit bureaucracies.

No doubt, when the director of biological sciences in Merrell's Cincinnati laboratory covered up the decline and death of a laboratory monkey, he did not intend to give cataracts to a six-year-old boy in New York. He was concerned to expedite government approval for his firm's drug. Similarly, the sales managers who instructed detailers to parry doctors' concern that MER/29 might be harmful intended to fill sales quotas, not to cause blindness.

These men were not even immediately concerned with profit. 'Fraud can be an illegitimate means to achieving any one of large range of organizational and personal goals when legitimate means to goal attainment are blocked.'<sup>45</sup> The routine nature of many acts that have ultimately tragic consequences makes it easier for company employees to ignore such consequences.

Street criminals do not usually lobby to have murder or muggings legalized but corporate law-breakers double as corporate law-makers, lobbying to prevent uncongenial laws. This process is particularly obvious in the United States but mercury poisoning at Minamata, asbestosis at Wittenoom and coal slag at Abefan prove that profit is the bottom line in most communities. Pharmaceutical lobbying ensures that laws governing the manufacture and sale of drugs either do not allow for criminal charges, or favour the corporations at the expense of the consumer, or decree only minimal punishment.

No one went to jail for thalidomide.

The corporation is insulated from the criminal process when proceedings are initiated and again when they are decided. Civil courts save corporations from the stigma of crime by out of court settlements (Australia) and consent decrees (USA), permitting corporations and professionals to avoid both trial and stigma.<sup>46</sup>

Emphasising street crime at the expense of corporate crime means that, although the victims of pharmaceutical drug addiction outnumber the victims of heroin by large margins, vastly more resources are directed to combating heroin addiction than to controlling benzodiazepines. Yet the two industries have much in common. Pam Gorring even argues that the public image of the heroin trade is not based on fact and that it is more apt for the pharmaceutical industry. She emphasises these points:

- 1. pharmaceuticals are handled by large, complex, international organisations;
- 2. the power brokers of these organisations corner supplies of a drug with a view to huge profits;
- 3. distribution is handled by a hierarchy, run by unknowns;
- 4. consumer welfare is important only to the extent that dead people can't use drugs and deaths are bad publicity;
- 5. the immorality of the transaction is that addiction is induced for profit; transient benefit or pleasure to the consumer only aggravates this immorality;
- 6. other criminal activities such as bribery of officials etc. occur ancillary to the main trade.<sup>47</sup>

John Braithwaite asserts that Gorring's fourth point 'goes too far'<sup>48</sup> but it is undeniably true that in developed communities, death is more salutary than suffering. Doctor/pushers, detailer/distributors and the manufacturer/Mafia successfully employ 'blame the victim' and 'blind them with science' tactics against living iatragenic addicts while the community reserves judgement.

But the benzodiazepines gained their mandate because they caused fewer deaths than barbiturates. If it can be shown that deaths do occur, then they lose their advantage over competing drugs. Certainly the first noticeable flurry of medical concern with the BZD problem in Victona derived from the discovery of local deaths in which BZD was the sole agent.<sup>49</sup>

Gorring also has history on her side. Elmer Bost, president of Hoffman-La Roche until the end of the Second World War and president of Warner-Lambert in the 1960s, revealed that Roche was heavily involved with the supply of morphine to the underworld between the World Wars. The firm was exposed in the Canton Road smuggling case, heard by the Mixed Court of Shanghai in 1925. Sir John Campbell argued in a minute to the League of Nations Opium Advisory Committee in 1927 that he 'had no doubt whatever that Hoffman-La Roche and

Company was not a firm to which a license to deal with drugs should be given.' In 1923, the OAC heard that firms in Germany, Great Britain, Japan, Switzerland, and the United States were turning out 'morphine by the ton, which was purchased by the smugglers by the ton.'<sup>50</sup>

#### Braithwaite summarises the historical record:

Some of the great pharmaceutical companies of today owe their existence to profits from the trade in heroin and morphine in an era which laid the foundations for the self-perpetuating cycles of addiction to these drugs in modern societies. The next generation might look back on the activities of Hoffman-La Roche in pushing Valium and Librium with disgust equal to what we feel today towards their heroin sales during the wars. It is fair comment to say that Roche has always been one step ahead of public opinion, making massive profits from drugs of addiction in the era before the drug becomes a matter of widespread public concem.<sup>51</sup>

Even without evidence of specific breaches of regulations governing the testing and marketing of drugs, the pharmaceutical firms are deeply involved in the addiction business where marketing imperceptibly shades into crime and the public is duped because the pushers wear white coats.

The pharmaceutical industry may argue that the rogue drugs represent only a small proportion of a grand total of drugs that are safe and effective. Survivors, public interest groups and criminologists will reply that coverup ensures that only a small proportion of wrongdoing and suffering ever becomes public. Are rogue drugs a flash in the pan or the tip of the iceberg? This particular question is unanswerable but we can say that so long as ethical issues take a low priority in marketing plans and budgets do not include a generous margin for thorough testing, then the risk is always present that a rogue drug will be inflicted on the public. Moreover, the risk will be unpredictable. One might say that drugs from firms with records like Eli Lilly's should always be treated with caution but very few of the industry majors have an unblemished record.

The smallest percentage failure is a one hundred per cent failure for the individuals concerned.

That is not a novel observation. None of the information you have just read is new: it has been published many times in many languages. The problem of rogue drugs is partly that the medical-industrial complex does not want consumers and legislators to know and partly that both consumers and legislators are reluctant to accept the facts. Consumers

want to be protected from the facts because they are frightening - legislators because they are challenging.

Perhaps we need to examine the facts again and again - until their meaning becomes incontrovertible - playing with them, like the colours in a Rubik's cube, until we form new patterns that will show us all the facets of the problem and permit us to take action at last.

# CHAPTER 4 PRINCIPLES OF PHARMACEUTICAL MARKETING

Lying is an act and - like every other act - demands all a man's skill. One must give up everything to it, one must first believe in the lie oneself, because only then can one convince other people.

Franz Kafka

#### WHO IS BEHIND THE MAN IN THE WHITE COAT?

Doctors and drug manufacturers shelter under the white coat of science. The association between pharmaceuticals, the medical profession, and science itself adds cachet in the eyes of the buyer and end-user. Pharmaceutical companies also have a more reticent style from other, more blatantly entrepreneurial firms. Pharmaceutical drugs are not obviously like soap powders.

But consider a packet of Valium as a product in the market and it is not essentially different from a packet of corn flakes. Detergents, cars, hamburgers and pills follow the principles of marketing and the principles of pharmaceutical marketing are still marketing principles.

Manufacturers who understand the marketing concept do not merely sell what they produce but produce what they know they can sell at a profit, whether the product is a disposable baby napkin or a lifesaving drug. And pharmaceutical manufacturers understand marketing very well: they use market research to find niches of untapped buyers; they use research and development to produce drugs to suit these niches; they use advertising and promotions to woo them; they multiply products under various labels and names to occupy shelf space and crowd out the competition.

Thus, despite well-known risks in mixing drugs, hypnotics are added to over-the-counter analgesics to produce a night-time version of familiar painkillers - mainly for the use of the elderly who are, of course, mainly women.<sup>1</sup>

Although the association between pharmaceuticals and scientific research enhances the image of these firms, the scientists they employ are subordinate to the firms' marketers just as engineers are subordinate to marketers in the car industry and chemists are

subordinate in the petrochemical industry. When firms commission scientists within academia to conduct research, as they do quite often, they fund a project calculated to whitewash their product. They do not easily accept negative results.

Far from providing permanent answers to certain problems of pain and disease, wonder drugs and miracle cures are expected to go through a product life-cycle - to appear, flourish, age and disappear like frisbees and skateboards - and to be replaced by new products. The cycle of pharmaceutical drugs is not as simple or as frivolous as the cycle of pastimes and playthings - but it is a cycle. 'Most biotechnology companies emphasize products that are likely to be profitable rather than those of greatest social need.'<sup>2</sup>

Let us push the published information about rogue drugs around until it forms a pattern: the principles of pharmaceutical marketing.

The benzodiazepines illustrate how drugs are developed where there is an affluent buying market. Dr. Leo H. Sternbach discovered Valium and Librium after long study of related compounds beginning in Poland in the mid 1930s and ending in London in the late 1950s.

The compounds that became chlordiazepoxide (Librium) were identified following a laboratory cleanup when some stray materials were sent for pharmacological evaluation and turned out to be both active and useable. The new compound was similar to meprobamate but also had anticonvulsant, muscle relaxant, sedative and appetite stimulating effects. It could achieve an anxiolytic effect at a dose below that needed for sedation and muscle relaxant effects. Valium was similar to Librium but five times more potent. The new drugs were used to tame mice, squirrels, dogs, dingos, turkeys, pigs, tigers, and lions - usually before a delighted press gallery.<sup>3</sup>

Valium and Librium triumphed in a market already softened by the razzmatazz accorded to Miltown, which was in the declining phase of its life cycle. They gave rise to a family of congene drugs that proliferated on pharmacy shelves, requiring ever more imaginative advertising. Every principle of pharmaceutical marketing can be demonstrated from this case - including failure to test for long-term safety.

We must not confuse the marketing concept with a free market, untrammelled except by supply and demand. The marketer's market is highly controlled, sometimes budgeted down to the fifteenth decimal point over a fifteen year period for a large multinational minerals or

petroleum project. Drug houses need to budget for the time required to develop, the time required to get approval, and lifetime of their patents - often more than twenty years. Marketing involves a budget that balances the total costs of research and development, materials, production, advertising and distribution against capital investment and anticipated profit. Scientific research, including safety trials, is thus only part of an overall marketing plan and must be subordinated to the total plan - including the budget and the timetable.

Planning is made easier in the pharmaceutical industry because roughly two thirds of the market is dominated by a handful of giant multinationals in Europe and America that are big enough to dominate prices in the remaining third. Even so, price fixing is occasionally reported.<sup>5</sup>

Since the decision to pursue over-the-counter or prescription profits is a basic part of the marketing plan, a market-wise firm might also want to control the schedules under which it is permitted to sell. This factor perplexed the German makers of thalidomide. 'The thalidomide disaster ... was in no sense inevitable. With an eye towards the bottom line, the company pushed thalidomide as a nontoxic tranquillizer that had none of the poisonous effect of the barbiturates then flooding the world market ... There were, however, early indications that thalidomide was worthless and produced a wide range of side effects.'6

When complaints from doctors and pharmacists concerning peripheral neuritis led to threats to have the drug put on prescription, Grunenthal's sales department noted 'unfortunately we are now receiving increasingly strong reports on the side effects of thalidomide, as well as letters from doctors and pharmacists who were to put it on prescription ... from our side, everything must be done to avoid this since a substantial amount of our volume comes from over the counter sales...'<sup>7</sup>

The fact that profit and not service is the goal among the drug companies is bourne out by their resistance to government regulation in the interests of public safety. The battle between the United States Food and Drug Administration and Eli Lilly over Oraflex (benoxaprofen) was part of a larger war between consumer groups and the pharmaceutical industry. The then President Reagan assigned the then Vice-President George Bush to hobble federal laws governing corporate America. Bush headed the Task Force for Regulatory Relief. Addressing a drug industry convention in June, 1982, he said 'I think we've started to see a philosophical shift, the end or the beginning of the end of this

adversarial relationship. Government shouldn't be an adversary. It should be a partner.'8

1982 was the year in which benoxaprofen was withdrawn because of severe unwanted effects on the liver, leading to one hundred and twenty-two deaths in the UK and USA. Nevertheless, in the first six months of that fiscal year, Bush did succeed in having the total FDA law enforcement actions reduced by two-thirds.<sup>9</sup>

Lithium's slow acceptance as the treatment for manic-depression is sometimes presented as the tragedy of a useful drug discovered in 1949 by an unknown psychiatrist in a small hospital in faraway Australia and only recommended to the FDA twenty years after its discovery. Certainly, the mineral had gained a nasty reputation in the United States when it had been used as a substitute for table salt causing at least three deaths and many poisonings. But, as we have seen, deaths and poisonings are not enough to halt the sale of a drug if it is profitable.

Lithium, as a naturally occurring substance, could not be patented and no one could comer the market on it. There was thus little profit incentive for the drug houses to invest in advertising, promoting and marketing it. Moreover the other wing of the medical-industrial complex saw lithium as a threat to profits.

Psychiatrists with a psychoanalytic bent, as most American psychiatrists were at that time, would no longer be able to keep people in therapy for ten, fifteen, and twenty-five year stretches. Cloaking self-interest under scepticism, they challenged lithium's efficacy. This is why, although lithium preceded the phenothiazines and the benzodiazepines, it was never hailed as a wonder drug.

Most marketing plans can accommodate a bargain sale. When the home market is exhausted or the general public realise that the product is dangerous, it can be dumped elsewhere - so long as there are no regulatory impediments. Two years after Bush's partnership speech, multinationals, encouraged by Reagan, used the UN committee system to bottle up WHO guidelines on hazardous exports. Dumping would be allowed to continue with pharmaceutical drugs as with pesticides.

The Dalkon Shield was not only dangerous in its barbed design, and attached to tails that drew infection into the sterile interior of the womb, it was also manufactured in less than ideal conditions, with poor quality

control, a defective manufacturing process and inadequate sterilisation.<sup>12</sup>

In the early 1970s, faced with increasing complaints about the Shield, including eighteen deaths in America alone, it was reported that the A. H. Robins Company offered the US Agency for International Development (AID) a 48 per cent discount if the Agency bought the Shield in bulk - unsterilised.

AID accepted the discount although recommendations to soak the device in disinfectant were not acceptable by US standards and only one set of instructions to sterilise were sent per package of 1,000 Shields. The devices were to be sold in Ethiopia and Malaysia but the instructions were in English, French and Spanish. Third World clinics that had bought the Shields on claims of a pregnancy rate of 1.1 per cent soon found their own rates to approach 14.8 per cent. Despite FDA pressure to withdraw the product, and to issue an international recall, the Shields remained fitted in 40,000 AID women and were still being fitted in Pakistan, India and possibly South Africa in the mid to late 1980s. <sup>13</sup>

Chloromycetin (chloramphenicol), marketed by Parke Davis, is an antibiotic with specific value for typhoid fever but it can cause aplastic anaemia, a serious and usually fatal blood disorder. Massive lobbying by journalists, doctors and politicians led to modest controls in the United States; it was then dumped in Latin America and sold for acne, athlete's foot and sundry infections with no warnings to physicians about the proper use or the hazards.

In Mexico, it was used both on prescription and for self medication, thus breeding a resistant strain of typhoid that began to spread from Central America to the rest of the world.<sup>14</sup>

Stern legal judgements in one country may have no impact on dumping elsewhere. Ciba-Geigy marketed clioquinol worldwide for various forms of diarrhoea but inappropriate doses of the drug causes SMON (subacute myelo-optic neuropathy), so ten thousand victims in Japan suffered blindness, paralysis, acute pain, paralysis, dementia and death. Despite paying out \$456 million in damages to the Japanese, the firm continued to sell its drug in Latin America, Africa and Asia.<sup>15</sup>

A general relaxation of standards goes with dumping. Thus, the recommended dosages are larger in Third World countries, the indications broader and the contraindications fewer. Sometimes the

formula is so outmoded that it is not even restricted in its country of origin because it has simply passed into medical history.

Until December 1986, when the Medical Lobby for Appropriate Marketing (MLAM) hit them with a flood of letters, Bayer was selling a tonic in Pakistan that was basically a light beer containing arsenic and strychnine.<sup>16</sup>

However, it is a serious mistake to think of dumping as merely a process by which multinationals unload to the Third World products that are unmarketable in developed countries. Dumping must be placed in a broader context of law avoidance. Products will be sold according to - and, if possible, beyond - the limits of the purchasing country. Any purchasing country. Legal advisers to the drug houses discriminate between tightly and loosely regulated countries - not between developed and Third World.

One repeatedly finds that developed countries are also the victims of law avoidance by pharmaceutical companies. By the end of the 1960s, Merck's Indocin was advertised in the US as 'highly toxic, able to cause perforation and haemorrhage of the esophagus, stomach and small intestines; gastrointestinal bleeding; retinal disturbances and blurring of vision; toxic hepatitis and jaundice; acute respiratory distress; hearing disturbances; loss of hair; psychotic episodes; coma and convulsions.'

However, in Australia and elsewhere, these warnings were weakened and omitted and Indocin, which should have been used only for severe arthritis, was being offered as an alternative to aspirin for the relief of pain following dental surgery, for tennis elbow, and tendonitis - indications not mentioned in American literature.<sup>17</sup>

In 1985, Britain forced Roche to dilute its recommended concentration of Hypnovel/midazolam but the company then marketed the stronger version to the United States under the name of Versed. By 1988, sixty-six people who received Versed/midazolam for minor dental work or diagnostic procedures had died of respiratory and/or cardiac arrest. 18

Although Grunenthal withdrew thalidomide from world markets in 1962, it continued to be used in Brazil where it is available over the counter. Although it is said to alleviate a painful unwanted effect of a drug used to treat leprosy, it is available among the poor for self-

medication and limbless children are proof that is still being used by pregnant women.<sup>19</sup>

The pharmaceutical scientist employed by a drug company is always under pressure because she or he must always fit in with the market plan. The plethora of elementary mistakes and inconsistencies in DES research submitted to the FDA shows that the regulatory authority was not overly conscious about scientific standards: it also shows that the drug companies did not expect to be forced to live up to them.

The FDA failed to query inconsistencies in both method and claims made between various researchers into DES and miscarriage. Some studies had no controls with a placebo while others did not isolate the effects of DES from the effects of other treatments such as bedrest, diet, nutrition and insulin in diabetic mothers.<sup>20</sup> The difference between a clean drug and a rogue is more good luck than good management.

The message from this is that the buyer cannot feel any more secure about the claims of a wonder drug than about the claims of striped toothpaste.

# **'SAFER THAN . . . ' IS STILL NOT SAFE**

Few products are sold on their merits. There has to be a selling line or unique selling proposition (USP) - that is what hidden persuasion is all about. The Marlboro advertisements refer to a vehicle for nicotine that induces mild physical pleasure, addiction, heart disease and lung cancer but the selling line is untrammelled virility. Many drugs are marketed on the fear of unwanted effects from existing drugs but they often turn out to have their own much worse effects or to be simply bad in a different way.

The Dalkon Shield, Oraflex, Selacryn and thalidomide were all marketed as 'safer than' a competitor just as thalidomide, meprobamate and diazepam were marketed on their alleged safety margin over the barbiturates. Doctors are still invoking the risks of barbiturates to justify their role in pushing the BZDS. But fewer deaths does not mean no suffering - it does not even mean no deaths.

The National Institute of Drug Abuse found at least 900 deaths in the US attributable to Valium in the twelve-month period 1976-77 plus another 200 attributable to Librium. There were also 54,400 emergency hospital visits due to overdose and misuse. This led the head of the Drug Abuse Staff at the FDA to conclude that at least as many people were being hurt by benzodiazepines as were being helped.<sup>21</sup> It took the state of Victoria another ten years even to admit that BZD deaths were possible.<sup>22</sup>

Such deaths are often complicated by the presence of other drugs particularly alcohol. When this is allowed for, the BZDs are obviously safer than many other drugs but still not safe.

If the concern for safety in drug research and development is not totally hypocritical, it is at least subordinate to other concerns within the marketing plan. Pharmaceutical scientists are subordinate to marketers even where safety is concerned. The sales department of DCBL decided to proceed with marketing thalidomide despite evidence of toxicity from Grunenthal and from their own tester.

'Distaval,' it told sales representatives, 'has a toxic effect of which you should be aware ... but there is no need to alarm the medical profession or discuss the matter unless it is raised.' DCBL's sales executive, J. Paton, said: 'It is not our job to educate the medical profession how to look out for various conditions. From a sales promotion point of view, the more we write on this side effect, the more it is likely to get out of perspective.'<sup>23</sup>

Wallace and Tiernan put a new tranquilliser, Dornwal, on the market despite strenuous objections from the firm's own medical director and against the advice of their own scientists that it could cause serious and possibly fatal blood damage.<sup>24</sup>

These examples suggest that the problem of responsibility in corporations is not insoluble - there is usually someone who decides to take the risk and that someone is often found in marketing.

The pressure to get products on the market subverts the normal testing process, with potential for disaster. In 1984, Riker was a pharmaceutical subsidiary of the 3M Corporation, which imposed a marketing goal that 25 per cent of each year's gross sales should be of products introduced in last five years. The rationale is to ensure that, as products pass through the life cycle, they will be smoothly replaced by new ones. Intervals without new releases can lead to pressure to market unsafe products or to schedule testing according to the market and not the exigencies of research.

Smithkline, a declining pharmaceutical giant, was trying to make a comeback in the 1970s. It had initiated rapid growth with Tagamet, an anti-ulcer drug, to become the fastest growing manufacturer of prescription drugs in the world. In 1978, total company sales doubled with Tagamet earning \$280 million; the following year, Tagamet earned \$490 million, and in 1980, with \$638 million it had become the world's largest selling prescription drug.

Smithkline wanted Selacryn to be a similar blockbuster and win a large piece of the multimillion-dollar blood pressure market. Marketed as safer than thiazides, Selacryn caused total kidney shut-down and death in former thiazide patients, due to a well-understood and predictable series of events.<sup>26</sup> Smithkline had selected a likely market, and conducted effective promotions but there was something lacking in its testing procedures.

The marketing mindset infects doctors who are supposed to protect the public. John Braithwaite publishes a delightfully ingenuous letter in his compelling study, *Corporate Crime in the Pharmaceutical Industry*. A trial doctor is reporting patient complaints about the side effects of indomethacin to Dr. Nelson Cantwell of Merck: 'these do not alarm me ... but I am afraid they will offer some practical problems in marketing this drug. Needless to say, I am very grateful for all of your kind efforts in regard to my trip to Japan.'

When Richardson-Merrell was seeking approval for thalidomide in the US, it recruited similarly compliant doctors. Although presented as part of a testing programme, the doctors were chosen by sales representatives who were instructed not to offer placebos for comparison with controls unless doctors asked. The doctors were told that they had been specially selected and that it did not matter very much if they did not keep records of their trials.

This relaxed method of selecting and briefing may explain other extraordinary cases: the doctor who was actually out of the country when normal studies were allegedly taken of a Pfizer trial patient who died almost immediately; the doctor who crossed his fingers when trying to fudge severe epigastric distress caused by Merck's Indocin; the doctor associated with Hoffman-La Roche, whose results fell overboard when he was out fishing on the eve of an FDA investigation.

Richardson-Merrell's chicanery over thalidomide should be considered in the light of the slightly earlier promotional scheme for MER/29. A Merrell inter-office memo said 'the objective in contacting

the armed forces was to lay the groundwork for the eventual sale of the product to the various hospitals serving each branch of the armed services ... We were not thinking here so much of honest clinical work as we were of a pre-market softening prior to the introduction of the product.' Their pharmacists knew that thalidomide could cross the placenta and was likely to damage the foetus but failed to conduct animal tests to make sure.

Misleading advertising inevitably accompanies medical fraud: since the direction of the message is predetermined, it doesn't matter who writes reports. A respected name is helpful but only if it accompanies a favourable opinion. The data presented by Richardson-Merrell to the FDA on thalidomide was definitely misleading: one crucial paper submitted under the name of an independent physician, Dr. Ray O. Nulsen of Ohio, was in fact written by the firm's medical director.<sup>29</sup>

#### ME TOO!

Drug companies, like any other market competitors, want a share of the profits and sophisticated marketing is one way of getting it. Many firms market drugs according to the crowded shelf principle: if you label one product with several different names and package it differently, your product occupies more shelf space and the public will buy more from you than if you filled an equivalent shelf space with only one item. A wall of apparently different soap powders may contain only two or three genuinely different products but appears to be offering a multiplicity of choices.

In the case of drugs, this is complicated somewhat by the intervening presence of the prescribing doctor who then functions like a buyer. The sales pitch is addressed to the doctor who simply does the choosing from the crowded shelf on behalf of the end user - the patient.

Many drugs tested are neither new nor necessary. Fewer than half the prescription drugs sold in the United States between 1938 and 1962 were effective for their claimed therapeutic purpose. Of 171 new products marketed between October 1975 and December 1977, only 6.4 per cent were classified by the FDA as offering 'important therapeutic gains'. An FDA survey of 348 new drugs marketed by the 28 largest US companies found that only 3 per cent have an important potential contribution; 13 per cent have a modest contribution, while 84 per cent have little or no contribution.<sup>30</sup> For every valuable drug, there are more than 100 valueless ones.

Figures like this suggest that delays in the release of drugs due to testing procedures are most unlikely to be depriving the public of lifesaving innovations despite periodic cries of outrage from doctors and pressure groups. Claims that regulations are depriving dying people of lifesaving drugs must be weighed sceptically.

Once a drug has succeeded in the market, other firms may decide to get around patents by copying it. Making congenes of someone else's success drugs is a good way to attract custom but the copies may not be exactly similar and the unwanted effects may be more hazardous. The 1,4-benzodiazepines are a rewarding group to copy - there are hundreds of them. And the 1,5-benzos are also being developed at present. Between 1954 and 1973, Roche had isolated a pharmacologically active and marketable group:

- clonazepam/Rivotril
- chlordiazepoxide/Librium
- diazepam/Valium
- flunitrazepam/Rohypnol
- flurazepam/Dalmane
- medazepam/Nobrium
- nitrazepam/Mogadon, Surem, Unicomnia.

As well, Roche had at least five additional derivatives.<sup>31</sup>

It has been suggested that the thalidomide disaster caused a decline in the rate of new drugs introduced in the early 1960s, especially in the CNS (central nervous system) area. It is also alleged that manufacturers were awed by the possibility that Roche had cornered the market with congenes for Librium and Valium. However, they soon overcame their reticence. Eventually, most firms had one benzodiazepine - or several. Consider this random and incomplete list:

- Abbott; Boehringer-Ingelheim
  - clorazepate/Tranxene
- Alphaphann oxazepam/Alepam
  - diazepam/Antenex
  - temazepam/Temaze
- Beecham ketazolam/Anxon
- Boehringer-ingelheim
  - oxazepam/Adumbran
- Hoescht diazepam/Lorinon
  - clobazam/Frisium

Protea - oxazepam/Benzotran

- diazepam/Pro-Pam

Roche - bromazepam/ LexotanRoussel - lorprazolam/ Dormonoct

Sauter - diazepam/DuceneUpjohn - alprazolam/Xanax

Warner-Lambert

- prazepam/Centrax

• Wyeth - lorazepam/Ativan

- oxazepam/Serenid

- temazepam/Euhypnos, Normison

Wyeth & Schering

- Iormetazepam/Loramet, Noctamid

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No one would ever claim that humanity is helped by reinventing a pill. Research to gain a share of an established market is part of 'me too' marketing. If one firm has a BZD, then everyone will develop one, just as, during the same period, everyone wanted an oral contraceptive. 'Most new products are molecular manipulations of existing patented drugs which enable a manufacturer to have its own patent in a lucrative market without offering patients advantages over existing therapies.'<sup>32</sup>

This is hardly even a trade secret. Smithkline readily admitted that "Compazine' and 'Stelazine' are very similar, clinically. Differences in doctors' attitudes to them are mainly due to our promotions.'33 Sandoz's Melleril/thioridazine is another example of the same phenomenon. Melleril is closely related to Sandoz's Serentil/mesoridazine but the former is marketed for schizophrenia while the latter is for 'not fitting in'.

Selling the same drug under many names for marketing purposes is hazardous for safe prescribing. The more than fifty different trade names under which thalidomide was marketed in different countries was the single most important factor in delaying an immediate halt to sales.'34 Associating two names, one a drug and one a disease, is relatively easy: DES/cancer! thalidomide/phocomelia! clioquinol/SMON! Valium/addiction! and so on. But learning thirteen or forty or fifty names is a daunting task for a busy medical practitioner whose main source of postgraduate education in pharmacology is handouts from pharmaceutical firms.

In England, before limited prescribing was introduced as an economy measure, three benzodiazepines were available under eleven names:

- diazepam was available as Alupram, Atensine, Evacalm, Solis, Valrelease, and Valium;
- lorazepam was available as Almazine, Ativan;
- nitrazepam was available as Mogadon, Ntrados, Somnite.<sup>35</sup>

The main effect of marketing congenes under numerous labels, with numerous attributes and indications to provide apparent choices, is to increase the already punishing burden on doctors and to decrease the possibility that they can ever make rational prescribing decisions. The doctors then become agents of the sufferings they are paid to cure.

Sufferers presenting to detoxification support groups commonly report that their doctors have prescribed first one and then another benzodiazepine to cure addiction symptoms, generally without noticing that their patients are addicted or recognising that the current drugs are related to earlier ones.

Marketing does not mean 'selling'. It refers to a total process that begins with the identification of a small group within the total buying population to whom a particular product may be sold. These target groups or market segments may be found by inference from demographic statistics.

If a population contains a high and growing proportion of women over the age of forty, there may be a segment in the market for hormone replacement therapy, calcium and fluoride preparations, heavier and more emollient cosmetics, lighter sanitary shields, hair dyes, singles dating services, and books about menopause.

If the market segment is people with high blood pressure, it may be interested in a drug like Selacryn. If the segment consists of travellers, they may need clioquinol but, by a little exaggeration of the risks of diarrhoea, the segment can be expanded to include everyone. Since life is full of stresses, sleeplessness, anxiety, grief, and grumbling bowels, almost anyone can be persuaded to want a BZD.

Identifying a gap in the market is the first step in the marketing process. Then comes designing a product to meet its alleged needs. In this sense, all modem pharmaceuticals are designer drugs, vastly more profitable and often more dangerous than the sort made in a suburban garage.

Imaginative promotion frequently enables the same product to fill a different gap in different markets. Clioquinol filled the relatively small gap for travellers' diarrhoea in the industrial countries from 1934 onwards but was an intestinal tonic in Japan after 1953 and was sold as a panacea in the Third World even after massive settlement between Ciba-Geigy and the Japanese in 1981.

The use of a hormone to treat infectious disease shows an unusual degree of lateral thinking; nevertheless, DES was used for both mumps in men and gonorrhoea in children before developing into a panacea for female ills in the 1950s when this versatile drug was used both to preserve pregnancies and to abort them.<sup>36</sup> As a female panacea, DES prefigured the benzodiazepines - doctors seem to believe that panaceas are the only solution to the female condition.

BZD illustrates market segmentation even more vividly: the same or closely related drugs are sold for housewives, college students, business men, the bereaved, pregnant women, hyperactive or tearful children or children going to the dentist, asthmatics, heart patients, road accident victims, geriatrics, surgical patients, and pets.

Marketing repeatedly creates needs by advertising. The cost of advertising and promotion often equals the cost of research and development, and production costs. In the case of BZD, promotion meant educating doctors and the public that old ways of coping were not satisfactory.

Having a good cry, a cup of tea, buying a new hat, going for a holiday, talking to a clergyman, or making love, became ineffectual, rustic solutions once the idea of the pharmacological fix was popularised during the Miltown era.

Marketing goes beyond creating wants - if existing diseases seem well covered, it can create new ones. 'Pharmaceutical companies even manage to invent new diseases as indications. Madison Avenue is able to respond creatively when the pharmaceutical company says "here's the cure, find the disease."'<sup>37</sup> When Lilly was looking for a new use for nortriptyline, an antidepressant called Aventyl in the US and Nortab in Australia, it called up a new disease called 'behavioural drift' recognised by a scratch list of trivial symptoms: crying, restlessness, lack of concentration, irritability, anxiety, feelings of worthlessness, and still more anxiety. This is a bit like 'not fitting in', the disease created for Sandoz's Serentyl.

Menopause, a naturally occurring part of aging in women, has probably been the target of cultural redefinition since humans took up residence in caves. Certainly, historical records and anthropological evidence from pre-literate cultures show a fascinating variety of responses to this phenomenon.<sup>38</sup> Second wave feminists are currently redefining it as a natural process.<sup>39</sup>

American doctors and drug companies took a new turn after World War II when they redefined menopause as a deficiency disease. The boom in HRT occurred in the postwar reconstruction when the industry was seeking uses for the variety of synthetic oestrogens that had been in abeyance since DES was developed in 1938. Dr. Robert Wilson, whose book *Feminine Forever* sold 100,000 copies in its first seven months, described menopause as 'living decay' that required hormone replacement therapy. His research foundation was receiving money from the Searle Foundation, funded by the manufacturers of norethynodrel, from Ayerst Laboratories, manufacturers of conjugated oestrogens, and Upjohn, who made medroxyprogesterone acetate.<sup>40</sup>

A promotional videotape put out by Pfizer reveals the redefinition process in action. It suggested changing the definition of depression to increase the market for psychotropic drugs. From four to eight million Americans suffer from depression, but if 'depression' can be made to mean 'absence of joy', then twenty million are suffering from it. The implication was that the disease is underdiagnosed and undermedicated.<sup>41</sup>

When consumer agitation, mainly by feminists, dulled the image of benzodiazepines in the 1970s, the marketers redefined them as drugs useful to the aged and as adjuncts to physical ailments.<sup>42</sup>

If there were a medal for the most elegant solution to the problem of creative iatragenesis, it must surely be awarded to the benzodiazepine family of drugs. First they make you well, then they make you sick, then they make you well until they make you sick again. Helga had the longest lasting BZD cycle I have encountered; she was put on the drugs for postnatal depression and is still on them twenty-two years later. Since she is only forty-five, still securely addicted and very frightened, she may live long enough to beat her own record.

The cycle of benzodiazepine addiction and withdrawal adds a new series of symptoms to those that the patient originally had - if, indeed, s/he ever did have anything as precise as symptoms. The doctor may then increase the dose of the pill the patient is already on or s/he may

devise a pill cocktail for these iatragenic symptoms. If she is lucky enough to substitute a long-acting for a short-acting formula or a stronger drug for a weaker one, the symptoms will subside - temporarily. This tactic is facilitated if the symptoms are amenable to being broken down into anxiety, insomnia or aggression so that the doctor can then call one pill an anxiolytic, one a hypnotic, and one a sedative - one drug for the price of three.

A single Valium advertisement epitomises this use of a drug to treat its own symptoms. The muscle relaxant properties of the benzodiazepines used long-term are so debilitating that support staff can often recognise addicts by intractable tiredness, poor posture and shuffling gait. Valium offered 'psychic support for the "always weary" with a photograph of a young housewife slumped in an armchair, listlessly stirring a coffee cup, with cigarette butts in the ashtray beside her, and an unread magazine in her lap.<sup>43</sup>

'Always weary' exactly describes what benzodiazepine addicts feel.

The uninitiate may wonder that Miltown, although first welcomed as providing symptomatic relief for thirty-one conditions ranging from alcoholism to typhoid fever, was found to have only placebo benefits.<sup>44</sup> Thereby hangs a principle. 'The diseases for which a drug is recommended are called its indications and the diseases for which it would be particularly dangerous to use it are contraindications. Pharmaceutical companies naturally have an interest in expanding markets by promoting wide indications and limiting contraindications.

Where the addictive pharmaceutical drugs enhance their own market success by creating the physical want to replace the one first created psychologically by promotions, antibiotic marketing accelerates the product life-cycle and the need for new drugs. Chloromycetin (chloramphenicol), marketed in Latin America for acne, athlete's foot and infected hangnails, bred a resistant strain of typhoid.

Resistant strains of gonorrhoea are rampant throughout the Third World, where individuals often cannot afford a full course of injections or tablets, or are so lulled by the first relief of symptoms that they stop treatment under the belief that they are already completely cured.

Doctors in the developed countries are not noticeably better.<sup>46</sup> The problem is not confined to general practice. In 1970 and again in 1972, hospital studies found that up to 60 per cent of antibiotic prescriptions were inappropriate.<sup>47</sup>

Inappropriate prescribing was still rife and still unremedied in 1992 when Australian microbiologists were concerned about the overprescription of Noroxin/norfloxacin for commonplace urinary tract infections when it should have been held in reserve for cases where the older antibiotics failed. Inappropriate prescribing of antibiotics leading to resistant strains of bacteria requiring the development of newer and better drugs enhances the antibiotic market just as addiction enhances BZD sales and inbuilt obsolescence boosts sales of consumer goods.

In chloramphenicol, Parke Davis had a very effective antibiotic for a very few infections - namely typhoid fever and hemophilus influenza. The preparation had many serious side effects including the often lethal blood condition, aplastic anaemia. If the disease to be treated is typhoid, then the risk of anaemia is worth taking; if the disease is the common cold, then such a risk is totally unacceptable.

The drug was promoted as a broad-spectrum antibiotic for everything from sore throats to acne. Parke Davis sold \$52 million worth of the drug under the name 'Chloromycetin' which represented the top drug earnings for 1951. The next year, the FDA said that cloramphenicol 'should not be used indiscriminately for minor infections.' By 1955, fatal side effects were well established.

Parke Davis misrepresented the FDA rebuke to its own sales representatives as the drug 'has officially cleared by the FDA and the National Research Council with no restrictions on the number or range of diseases for which Chloromycetin maybe administered.' In 1967, although 10,000 appropriate cases occurred annually in the US, 3.5 to 4 million Americans were being dosed with it annually. In 1975, 93,000 prescriptions were written for upper respiratory infections alone. In 1986, it was being dumped in Latin America.<sup>49</sup>

Indocin, Merck's highly successful anti-arthritic remedy, was introduced in 1963 and advertised as effective for many conditions when proven effective in only four. Merck must be credited for excluding children from their target market 'since the experience with Indocin is limited'. In fact, there had already been enough experience to pick up several child deaths.<sup>50</sup>

In the case of new preparations for which there is no apparent use, the indications may have to be contrived - the disease must be invented. Since DES was the first synthetic oestrogen, synthesized in 1938 but not patented, it was up for grabs. The drug companies were competing with each other to register uses - including lactation

suppression, prostatic cancer, and hormone replacement therapy for postmenopausal women. Ely Lilly, the major producer of DES, marketed it for miscarriage with cruel results.<sup>51</sup> Anabolic steroids were also, at first, drugs without indications. In 1984, the Association of Netherlands Pharmaceutical Manufacturers rebuked Organon for promoting an anabolic steroid to build appetite in underfed children in Bangladesh and Kenya.<sup>52</sup>

#### **HIDDEN PERSUASION**

Marketing needs to communicate the existence of products to the buying or prescribing public. This may involve identifiable advertising. It may also involve promotional activities such as subsidising peak breath flow meters for asthmatics. It could involve public relations such as placing unsourced newsworthy items in the media or commissioning someone to write an apparently disinterested book on menopause that just happens to mention only the drugs produced by a single company or an apparently disinterested book on manic-depression that attributes special competence to a single clinic. It may involve training an aggressive face-to-face sales force to hand out brochures, bric-a-brac and brave words. And it may involve funding scientific research as a public relations exercise that ends up blurring the line between science and PR.

Pharmaceutical companies set out to enhance their credibility by sheltering behind the white coat of science and end up by discrediting it. Marketing may even disguise the inadequacies of research. According to Diana Dutton, 'Studies of particular clinical innovations have shown that the poorer the data and the less rigorous the evaluation, the more exaggerated the claimed benefits tend to be.'<sup>54</sup>

There is a certain coyness in some quarters in admitting that advertising really does influence doctors. A study demonstrating that doctors do not discriminate between the reliability of advertising and of editorial content in medical journals seems to indicate that doctors attribute the same credibility to advertising as to professional writing. Advertising has vast influence. This appears to be counteracted by a study demonstrating that doctors pay SO little attention to they advertisements that cannot identify drugs in advertisements if the names are deleted. 55 Advertising has no influence. The overwhelming single argument that advertising has real power is the strength of the protests if governments threaten to regulate the industry.56

Many studies show how to reconcile these two extremes.

Doctors mostly began to prescribe new drugs under the influence of detailers, medical journal articles and medical journal advertisements.<sup>57</sup> A significant number of survey doctors expressed positive beliefs about drugs still in use although proven to be neither useful nor safe. Since these views could not have come from professional literature, the study concluded that they were influenced by commercial, non-scientific sources of information such as advertisements and detailers.<sup>58</sup>

This pattern may explain why benzodiazepines are still prescribed for depression. The early 1980s saw a progressive broadening of cautions and contraindications recommended by the manufacturers including a warning that the drugs should not be prescribed for depression because relieving anxiety might disinhibit a person's tendency to suicide. Fet, surveys of psychotropic drug use consistently show the drugs being used to treat both anxiety and depression as if they are the same. Some surveys go further, showing how that the prescriptions are 'not always appropriate or effective'. Fet

Advertising is hostile to female patients. Repeated surveys show that pharmaceutical advertising presents women as passive, self-indulgent, slow-witted, prone to hypochondriasis, and unable even to perform the rather simple tasks that the traditional feminine role requires of them without psychotropic drugs.

This stereotype also appeared in general advertising until market research revealed that several new target audiences had emerged - working wives and single women. General advertising began to reflect these new developments but pharmaceutical advertising, aimed at doctors who prescribe rather than at purchasers and end-users, remained hopelessly behind the times.<sup>61</sup>

Advertising is not the only reason why twice as many prescriptions for psychotropic drugs are written for women as for men - but it is certainly a contributing factor.

Oraflex is a dramatic example of effective advertising. Pharmaceutical marketers welcome diseases that require lifetime maintenance. Arthritis is one such disease. Thirty-two million American adults and children suffer from varieties of arthritis including sixteen million osteo-arthritis sufferers, most of them elderly, most of them female. This was the target market. In the early 1980s, it was valued at \$711 million. Two new non-steroid anti-inflammatories appeared in

1981-82: Pfizer introduced piroxicam/Feldene and Lilly introduced benoxaprofen/Oraflex.

Neither drug differed markedly from others of their type, and they cost more, but aggressive advertising won each a 25 per cent market share in their first year's sales. A high visibility marketing campaign led financial analysts on Wall Street to predict that Oraflex/Orpren would push Lilly's stocks up. The 1982 prediction was that sales would be \$250 million annually by 1985. And, indeed, sales sky-rocketed under heavy promotion. In the first twenty-one days of US sales, 64,000 prescriptions were filled. Oraflex was released in May 1982 and withdrawn in August.

The FDA was able to demonstrate that Eli Lilly had launched benoxaprofen in an eleven million dollar campaign despite detailed knowledge about its toxicity to the liver, including numerous overseas deaths.<sup>62</sup>

Professor Graham Dukes, world authority on side effects of drugs and drug-induced injury, comments that cases like benoxaprofen impose a new responsibility on manufacturers.

There is no doubt at all that ... astute selling techniques can substantially and sometimes dramatically alter a physician's prescribing patterns ... This factual situation, in which the behaviour of the physician in choosing and using drugs is determined to such a large extent by commercial influences, must result in the existence of a series of duties and responsibilities on the part of the drug manufacturer, irrespective of whether or not such duties have been created by statute.<sup>63</sup>

Despite its proven capacity to influence, few countries scrutinise pharmaceutical advertising before it is published although most control it after publication. Hence improper advertising has often done actual harm before anything can be done.

Surveys of major drug advertisements in the mid 1980s found that 50 per cent contravened relevant regulations, although often on minor points, and enforcement of the regulations was uncommon. It concluded that the manufacturers' voluntary code of advertising practice was insufficient. Now it may be argued that trivial breaches of regulations are unimportant but neglect of regulations in an area of health or safety creates an atmosphere in which health and safety themselves come to seem trivial.

In 1976-77, the year in which nine hundred American deaths were attributed to Valium, Lilly's Darvon/propoxyphene was linked to 1,100 deaths. The National Institute of Drug Abuse concluded that Darvon is an even bigger danger than Valium. Lilly made the standard defence, the problem is not in the drug but in the user: the drug is safe and useful if properly used. The public interest campaign to ban Darvon argued that it cannot be properly used because of its advertising.<sup>65</sup>

This is surely the core of all arguments about drug pushing: if the advertising, the promotions, the public relations and the face-to-face pitch all magnify the indications and minimise the contraindications, the drug must inevitably be misused. In 1979, the FDA ran a campaign through mailouts, advertisements and drug company representatives to reduce the prescribing of this habit-forming, ineffective and easily overdosed drug but found that doctors had become habituated to Lilly's first message and were not responding to the corrective campaign. Ten years later, Darvon was still on the market and brought in one million dollars in sales.<sup>66</sup>

This phenomenon entirely undercuts arguments for not scheduling the BZDs as addictive because they are all right if properly prescribed. They can never be properly prescribed without a massive, highly sophisticated campaign to control advertising and to re-educate doctors - and perhaps not even then.

When oestrogen was first synthesized in 1938, it had no obvious practical use so it was tried for pregnancy testing and preventing miscarriage. By 1960, it was established that hormones taken in pregnancy could induce birth defects. In 1973, the FDA issued a warning against these uses and two years later the agency withdrew approval of any use of hormones during pregnancy. But established habits are hard to break. In 1972, before the ban, 588,000 hormone prescriptions were written in the US for pregnant women; after the ban, in 1975, the figure had dropped to 533,000.<sup>67</sup>

The somewhat ineffectual nature of advertising regulation is further weakened by failure to regulate other facets of promotion. Take the case of Indocin. The salesforce was paid \$2.80 on every extra 1,000 Indocin sold and instructions to sales representatives were far in excess of what was approved by FDA. There seems very little point in approving the information on the packaging - which few people read and even fewer understand - if the sales pitch is going to present disinformation. After examining face to face selling, John Braithwaite

concluded, `. . it remains a major irony that the most influential method of drug promotion is the least constrained by law.'<sup>69</sup>

The advertising, promotions and sales budget of drug houses are a major part of their budgets. In 1973, twenty pharmaceutical companies gave 12.8 million gifts to healthcare professionals and over 2 billion samples of free drugs. The FDA estimated in the early 1980s that the drug companies were spending six to eight thousand dollars annually on each doctor in the US to promote prescription drugs. The total was more than one billion dollars - more than US government expenditure on medical schools.<sup>70</sup>

Although some of the gifts are sophisticated and amusing or educational, many of them are trumpery. The moral significance of a plastic model of a coccyx is not immediately obvious until it is viewed not as a gift but as a bribe. The relative costs are salutary. The device is worth nothing to the doctor, who would not bother to buy it if it had not been donated; it is worth cents to the drug house; it may be worth a life if it is advertising Orpren and the doctor prescribes the drug to an arthritic grandmother; finally, the cumulative cost of all the gifts is an important surcharge on a nation's drug bill.

'When the proportion of GNP spent on health is never enough to provide adequate care for everyone, it is tragic to see health care resources wasted on activities which often do as much harm as good.' It is also tragic to see members of our most highly educated profession so easily seduced. 'Doctors like new toys to play with.'<sup>71</sup>

Public relations are more subtly harmful than advertising, promotions and face-to-face selling. To begin with, PR is less visible than the other marketing techniques. The press can be inveigled into publicising prescription drugs that could not be advertised to a public who cannot easily distinguish between news and press releases. Moreover, since journalists often fail to discriminate between drug success and claimed success their stories may be well-intentioned but dangerously misleading. They may unwittingly create a situation that is hard for responsible doctors to correct. The press usually sees drug successes as news but failures as not news and corrective messages as a trivial waste of time.

Drugs like meprobamate and the benzodiazepines that lend themselves to magical sideshows in the zoo and factitious controversies about the morality of happy pills get more coverage than their research findings merit.<sup>72</sup> Analysis of tranquilliser coverage in the US mass

media shows the press's function in stimulating interest that would inspire patients to ask doctors for tranquillisers, thus reinforcing advertisements directed to doctors.

Before buying the Dalkon Shield, A. H. Robins knew that the Dalkon Corporation had tested the device for an average of only five and a half months when the accepted time was one year; Robins also knew that the pregnancy rate was not 1.1 per cent but more like 3.1-5 per cent. Nevertheless, they bought the product and advertised it on these false claims. Salesmen were told to fudge the copper content of the device and say that its components were confidential.

Having been developed with fraud in the laboratory, MER/29 was launched to heavy promotion and misleading advertising. One advertisement, run in seven major medical magazines, proclaimed that MER/29's use in over 300,000 patients 'reaffirms the safety margins established in early laboratory and clinical data.' At that time the firm knew of at least four cataract cases and numerous complaints about red, watering eyes and blurred vision, skin scaling and falling hair.

When reports of MER/29 blindness became difficult to suppress, Merrell issued a pamphlet to deceive its salesmen – 'Simple Question Counters 90% of Side Effect Questions' advising this ploy: 'When a doctor says your drug causes a side effect, the immediate reply is: "Doctor, what other drug is the patient taking"' Merrell began to minimise hair changes as 'thinning hair' and advocated that salesmen cultivate enthusiasm for the product. 'YOU HAVE NO REASON NOT TO BE ENTHUSIASTIC - YOU HAVE NO REASON TO GIVE A 'TONGUE IN CHEEK' DETAIL ON MER/29. YOU HAVE A PRODUCT THAT MOST OF YOUR COMPETITORS WOUUD REALLY LIKE TO HAVE. YOU OWE IT TO YOURSELF - TO YOUR COMPANY - TO THE MILLIONS OF PEOPLE WHO NEED MER/29, TO BE ENTHUSIASIIC!!!'<sup>75</sup>

Companies caught out on misleading advertising may stonewall. In (northern) Summer 1982, the FDA compelled Ely Lilly to send out a series of 'Dear Doctor' letters to correct the message of promotional press kits that minimised the adverse effects of Orpren and exaggerated its benefits. The company had also gone far beyond the limits on labelling products of unproven clinical value.

The FDA persisted with inquiries about the press kit and promotional material and found them even worse: careful wording, selective emphasis, inappropriate headlines, and minimisation of adverse information about the drug created a false impression that

deceived the media. The company was then asked to send out clinically verified information within the guidelines for approved labelling.

Impending exposure of homicidal negligence can even lead to intensified promotional efforts. When Lilly was forced to withdraw Orpren because of deaths in Europe, they put out a 'Dear Pharmacist' letter requesting retailers to hold their stocks but still said that the drug was safe.<sup>76</sup>

From July to November 1979, when Smithkline was neglecting to report adverse reactions it was blitzing doctors through the mail with free samples - attempting to eat into the thiazide market, still insisting 'no causal relationship between Selacryn and abnormal liver function tests and jaundice.'77

Readers will recall that thalidomide was marketed as safer than the barbiturates. At its launch in October 1957, it was described as 'completely non-poisonous ... safe ... astonishly safe ... nontoxic ... and fully harmless' despite early warnings. Although the FDA and Dr. Frances Kelsey kept it out of the US, phenomenal worldwide sales led to increased advertising that continued the safety theme unabated. Two hundred and fifty thousand leaflets mailed in 1960 claimed thalidomide was 'nontoxic', 'harmless even for infants' and 'harmless even over a long period of time' despite complaints coming from around the world. The most common of these was peripheral neuritis - the condition that Dr. Kelsey had found was associated with phocomelia. <sup>78</sup>

Advertising is readily available to scrutiny. Public relations efforts are harder to pin down without the resources of investigative journalism. In 1973, when suspicions about a connection between hormone replacement therapy and cancer were beginning to reach the public, Sondra Gomey and Claire Cox published another pro-HRT book called *After Forty*. It could have been another publication of the burgeoning women's health movement that had made history with the now classic collective publication, *Our Bodies, Ourselves*. <sup>79</sup>

Sondra Gomey's credentials for collaborating on such a book included her position as Executive Director of the Information Centre on the Mature Woman, a 'service for media' provided by Ayerst laboratories, manufacturers of Premarin - the so-called 'natural oestrogen'. Ayerst was acting in defiance of the Pharmaceutical Manufacturers Association code of ethics, which prohibits the promotion of prescription drugs directly to the public. Ms Gomey's role was

providing free filler items lauding HRT to journalists in the mass media who used the material without attributions.<sup>80</sup>

Small Comfort, Professor Mickey Smith's study of the minor tranquillisers resembles After Forty in a number of ways. Both books appeared when the preparations discussed were coming under popular attack and both are curiously evenhanded and somehow above the debate that made the books topical. Professor Smith argues that the alleged problem with happy pills is simply cultural lag. Technology advances more rapidly than culture's capacity to adjust to change. Addiction is barely mentioned.

It is true that the use of happy pills is by no means new. Taking prescriptions recorded in the US back as far as they will go, it seems that, although the minor tranquillisers have replaced a more varied group of drugs that included opioids, bromides and barbiturates, the proportion of prescriptions for psychotropic substances has been remarkably constant since 1880. But by blaming the inertia of social scientists in not helping the medical profession, Smith shifts attention away from other groups who have not helped. He might equally well have said the clergy have not helped or even that the pharmaceutical industry has confused doctors with meretricious advertising.

Smith uses blanket terms like 'society' but avoids reference to the industry even when it would be logical to do so. ". . . the patient, the physician, and society as a whole have wrestled together (and too often independently) with identifying the proper role for the minor tranquillisers.'82 Yet it is the industry that restricts information available for debate, defines the issues, and influences regulatory control through lobbying, coercion and sometimes outright bribery.

The Kefauver hearings in the United States Senate began in 1957 as an inquiry into pricing and competition in the pharmaceutical industry. By the time its twenty-six volumes of hearings were completed, it had shifted focus to a major restructuring of the FDA. One of the most interesting features of these hearings did not emerge until Senator Kefauver's death in 1963. When his safe deposit box was opened, it was found to contain \$300,000 in stock from the drug companies he was investigating.

Appearing soon after Nader's group, Public Citizen, put out *Stop Valium, Small Comfort* subtly conveyed the impression that, while meprobomate is definitely and even ludicrously addictive, there is no similar case against the benzodiazepines. At the time when Professor

Smith was writing, there were no fewer than seventy research reports, reviews and case studies to show that the BZD family is as addictive as the barbiturates and meprobomate. As early as 1964, the World Health Organisation identified benzol as 'a category of drugs being capable of giving rise to dependence of the barbiturate type'. The first studies indicating addiction appeared in the year that Librium was released on sale.<sup>85</sup>

A careful analysis of Smith's text would reveal that psychological Calvinism is a decoy, set up to draw fire away from more worthy targets. These anomalies might lead one to examine the author's credentials. His published works include *Principles of Pharmaceutical Marketing*.

Attacks on advertising are sometimes seen as attacks on free speech but speech that damages others has never been free: slander attracts penalties and so does incitement to breach the peace. Freedom of speech is always balanced against other considerations.<sup>86</sup>

Braithwaite observes that companies do not like to upset doctors: 'Our concern is not so much avoiding misrepresentation ... but avoiding those kinds of misrepresentation which upset doctors. The company's credibility is all-important.'<sup>87</sup> We have already seen that most doctors can be bribed into lethal complacency by a plastic bone and some are fortunate enough to trade their integrity for overseas trips and research funding.

It is by no means certain what kinds of representation do upset doctors, since they so rarely criticise promotions but a statement from a medical director for Squibb suggests that their threshold of tolerance is very high. 'Anything that helps to sell a drug is valid.'<sup>88</sup> No drug house ever went broke underestimating the acuity of the medical profession.

'Never look a gift horse in the mouth', runs the adage. Whatever the faults of advertising and detailing, they save doctors from the obligation to sift through journals, trying to find research findings and make up their own minds about drugs.

In the case of the benzodiazepines, the product itself offers hidden benefits to the doctor that outweigh possible harms to the patient. The first suggestions that doctors were driving the tranquilliser boom appeared in 1960. Prescribing doctors were thought to fall into four types:

- 1. those who have trouble communicating
- 2. those who have no alternative to offer
- 3. those who want to please
- 4. those who cannot stand anxiety themselves.<sup>89</sup>

Some enterprising agency must have sensed this when they wrote copy for a Valium advertisement in a doctors' magazine saying that it produced 'a less demanding and more compliant patient.'90 Research continues to support the proposition that benzodiazepine prescribing is not rational.91

#### **GREASE AND VARIANCE**

If any reader still had a lingering sentiment about white coats and pure ideals, the phenomenon of bribery should dispel it. 'Bribery is defined as the giving of rewards beyond those allowed by law to entice a person with a duty of trust to pervert, corrupt or compromise that trust. Extortion is defined as the soliciting of a bribe.' That is, bribes are not 'grease' payments to get bureaucrats to do the job they are paid for but 'variance' payments to get someone to nod at wrongdoing.<sup>92</sup>

Bribery can occur at any stage in the research and development, licensing, manufacture, distribution, or sale of drugs but it is best seen as a device to further the marketing plan. Doctors get overt bribes, ranging from silly, to substantial, to subliminal: most get coccyxes and calendars, some get trips and jobs. Gifts shade into inducements and inducements shade into bribes as marketing draws doctors into the medical-industrial complex.

Marketing is not illegal - nor should it be. It is intrinsic to modern economies and cannot be excised. But the culture of marketing is incompatible with the culture of science and it is rather easy to turn the only averagely endowed practitioner into a mere technocrat or front who performs without conscience, affection or inspiration as we have seen in the marketing of materiel for germ and nuclear warfare to Saddam Hussein.

Marketing as it is now practised is conducive to criminal solutions to conflicts between public risk and private profit. Every phase of marketing provides an occasion to break the law.

Where the products developed for marketing bear on public health and safety, regulation is essential. The case for increased regulation is poignantly clear when we think of the thalidomide babies, the wombless women, the blinded arthritics, the demented, and the prematurely dead. The risk of corporate crime in the pharmaceutical (or any other) industry increases with its commitment to so-called laissez faire capitalism.

Planning and control are the essential nature of the giant, multinational corporations - whether they produce cars, petrochemicals, drugs, or a diverse range of goods. Their commitment to the free market is strictly liturgical except in the adamant refusal to accept regulation in the interests of public health. In the USA, attacks by corporate lawyers and scientists on the personnel of the FDA indicate an unedifying and total failure of social responsibility.

In Australia, the problem is sloth and stinginess. The cost of ensuring drug safety and efficacy is too high while no one cares enough about the issue to lobby vigorously. Even concerned individuals in government and the public service find cost and indifference - the twin poles of the pharmaceutical drug problem - irreconcilable. Yet they must be reconciled if we are to stop the endless repetition of rogue drug tragedies.

The simplest argument is from cost benefits. 'It is not the responsibility of private businesses to protect the interests of society as a whole,' writes Diana Dutton, 'and it would be naive to expect them to do so. For companies, medicine and clinical research are simply good investments. Yet in medicine, good investments may result in bad health policy.'93 Governments will always subsidise the medical-industrial complex through the health dollar but they must shift their focus from what benefits the industry to what benefits patients and the public purse. Industry can look after itself: patients and taxpayers cannot.

# CHAPTER 5 WHITE-COLLAR CRIME

Some circumstantial evidence is very strong, as when you find a trout in the milk.

Henry David Thoreau

### THE DANG DOGS WERE DYING LIKE FLIES!

White-collar crime has been studied for at least a century but its importance is not much recognised outside academia except when an unusually large embezzlement or tax fraud occurs. As long ago as 1895, A. R. Barrett showed that American banks were losing more from embezzlement than from robberies and it is currently true that white-collar criminals kill more people and steal more money than the more feared blue-collar offenders.<sup>1</sup>

Among the various attempts to make sense of this phenomenon Braithwaite's differential power analysis is both plausible and attractive: white-collar crime results from having a very great deal of power while blue-collar crime results from having too little. However, wrongdoing in the drug houses is not confined to the most powerful strata of the industry. Indeed, there is some evidence that one function of middle management is to accept responsibility for decisions that top management are ashamed to own - hence the quip that many firms have a manager for going to jail.

It may be true that great power (or even any power) creates opportunities to engage in profitable crimes both against and on behalf of the company<sup>3</sup> but corporate crime is more often systematic than opportunist. Crimes committed by individuals against the company require a different explanation from crimes by company employees against the commonweal. In the former case, theories such as differential power may take us further than we need to go: familiar human motives like fear, greed, and sloth might be more useful. In the latter case, the drug house executive is often under a clear, if unwritten, obligation to commit crimes on behalf of his firm.<sup>4</sup>

Some conduct does not fall within legal constraints but is still blatantly unethical. In 1965, after thirty years of evidence that clioquinol was dangerous, Ciba added a package warning for the UK market that the drug was not suitable for animals but continued to sell

it for humans.<sup>5</sup> There is a wry parallel here with DES: when gynaecologist Karl J. Kamaky reported to E. R. Squibb and Sons that the dogs he fed DES were 'dying like flies', the firm urged him not to give up but to try the drug on women instead. He did.<sup>6</sup>

Marketing is not noted for its puritanical observation of a code of ethics. Self-regulation in any industry is usually a license to put business before ethics and marketing is largely self-regulated. Commenting on the Australian Pharmaceutical Manufacturers Association Code of Conduct, Professor Robert Moulds told the House Inquiry that there were problems enforcing it. 'The penalties range from a slap on the wrist to two slaps on the wrist, basically. So it, is a little toothless.'

Nevertheless, there are a few legal and regulatory constraints on what may be done in the way of making and selling drugs. Rogue drug tragedies are usually the end result of systematic breaches of these constraints by marketers who already know both the credentials of the drugs they are sponsoring and the weakness of the constraints.

Merrell knew of thalidomide's risks from Europe when they took it to the FDA in the United States; Eli Lilly knew about benoxaprofen and Robins knew about the Dalkon Shield. Nevertheless, the firms fought strenuously for the right to sell these products, revealing not only contempt for the lives that might be risked but confidence that the law was inadequate to punish likely harms.

Given that drug house crime is systematic, we usually find several abuses involved in the promotion of any one rogue drug. Nevertheless, it is useful to look at the elements of crime separately because they result from decisions in specific parts of the organisation and are parts of a procedure for which certain employees are responsible.

#### **OOPS! FAILURE TO RESPOND TO EARLY WARNINGS**

Rogue drug tragedies seem to come as a surprise but most of them occur after early warnings have been ignored. The companies know in advance of commercial release that their product is suspect or frankly dangerous and suppress evidence provided by their own scientists, by franchising companies or by trial doctors.

Lilly's conduct in respect of Orpren/benoxaprofen was part of a habitual pattern of frustrating the intentions of the FDA, which reported in 1979 that when it came to submitting incomplete reports of adverse drug reactions (Drs), Lilly had the worst record of the ten drug companies studied. Lilly did record the reactions but in 61.8 per cent of 324 serious ADRS, the dates of starting the drugs and observing the symptoms were omitted. These omissions were systematic and calculated to prevent anyone making inferences about the causal sequence of the adverse reactions. (What came first, the drug or the reaction?)

Benoxaprofen was only one of four drugs that Eli Lilly had failed to report on in 1981. Investigators alleged that 65 of 173 Orpren reactions submitted to the firm by doctors had not been reported to the FDA at all; not all the effects mentioned in initial application were mentioned in the final submission; not all the effects in final submission were in the initial application. This added up to a gross understanding of the problem.

In 1979 Lilly had also been involved in marketing Darvon, a drug that was criticised as less effective than aspirin in killing pain and more effective than heroin in killing people. Over six months before benoxaprofen went on the American market, an FDA investigator recommended criminal prosecution of Lilly for failure to submit both premarketing and postmarketing adverse reactions on Darvon and another Lilly drug, Monensin.

Eli Lilly knew about a variety of unwanted effects for benoxaprofen ranging from slight to fatal reported in the UK before it launched an eleven or twelve million dollar, high visibility US marketing campaign for Orpren in 1982. The company clearly knew that the drug was dangerous even while it was negotiating to obtain FDA approval.<sup>8</sup>

The company continued to market the drug for fifteen months after they knew of its dangers. Richard D. Wood, chairman and chief executive officer of Eli Lilly testified at the trial over the death of an 81-year-old American that he had personally decided to launch benoxaprofen on the American market after reading about the deaths of five elderly women in Northern Ireland.<sup>9</sup>

DES had already been shown to be carcinogenic in mice and dogs when E. R. Squibb employed Dr. Kamaky for its attempts to prove that the synthetic oestrogen prevented miscarriage. His early studies reported that the foetus shared with the mother in the effects of DES, confirming a fairly common suspicion that anything smaller than a golf

ball crosses the placenta. This early warning sign was ignored by Squibb and other major manufacturers.

United States law required adverse reactions to be reported 'as soon as possible, and in any event within 15 working days' from the first notification of reactions. When reports began to come in about Selacryn, Smithkline did not notify for 105 days and then buried the information in the third volume of a seven-volume, 2,500-page routine quarterly report where it was undiscovered for several months. The drug was recalled from the US market after 60 deaths and 513 patients with liver damage during an eight-month marketing life.<sup>11</sup>

The story of clioquinol began in 1935 when two Argentinian researchers reported patients who developed bilateral nerve damage after using Ciba's dysentery drug. Other studies showed that it not only had no special benefits in diarrhoea but actually caused it. The twin themes of uselessness and danger persisted in reports until 1960, ten years before Entero-Vioform was withdrawn in Japan, when the FDA advised that its use be restricted to amoebic dysentery and that it be withdrawn from over the counter sales in the US and put on prescription. Ciba withdrew the drug from the US market in 1972.

Ciba told Japanese physicians that the drug was safe and effective: it was safe for children; it was scarcely absorbed into the intestines; any side effect was temporary and therefore clioquinol need not be discontinued. And all this despite the fact that the inventors of the drug warned in 1944 that it must be rigidly controlled and not used for more than 10 to 14 days.

The messages about clioquinol reached a crescendo in the Tokyo District Court, which said 'As to the circumstances that only in Japan has incidence of the disease been observed, the explanation is that only in this country were the drugs containing clioquinol used by large numbers of people in large doses over long periods.' The Japanese could have avoided large numbers, large doses, over long periods if Ciba had simply acted on their copious early warnings.

Before Grunenthal marketed thalidomide, the company knew that it caused a wide range of side effects. Doctors wrote scathing letters within weeks of the drug's release but their letters were ignored. So were British research findings.<sup>13</sup>

A more conscientious analysis of the available information led Dr. Kelsey to withhold FDA approval in the United States but Merrell

persisted in trying to get approval for thalidomide even when Dr. Kelsey drew their attention to a British article on peripheral neuritis in February 1961.<sup>14</sup> Increasing numbers of legal cases are producing information about corporate crime among BZD manufacturers. These are not only civil suits by addicts but criminal cases invoking diminished responsibility because of BZD use. The Benzo defence is beginning to rival the Clockwork Orange defence in crimes of violence.

Upjohn's Halcion/triazolam, a short-acting BZD, marketed as a hypnotic, was one of the first BZDs to be taken to court. It is believed to cause peculiarly violent psychotic states, <sup>15</sup> ranking first in a 1990 FDA analysis that compared the number of violent acts associated with 329 prescription drugs. <sup>16</sup>

William Styron, whose graceful memoir of depression, *Darkness Visible*, unsettled even the American psychiatric fraternity, was addicted to Halcion and consuming large doses of it when he sank into the suicidal depression that almost destroyed him.<sup>17</sup>

The drug's license in Holland was revoked in 1979 but reinstated in 1990 for a lower dosage despite continuing worldwide concern. By then, marketing had established Halcion as the best-selling BZD hypnotic in the world.

Consumer activists in the USA had been demanding its withdrawal for a decade, claiming that Upjohn had subtly concealed damaging findings. Upjohn belatedly admitted that they had suppressed evidence on triazolam-induced psychosis from a 1972 trial. The most recent wave of agitation has won tighter and more visible warnings for the USA and Australia but not a withdrawal from sale. The drug's license was suspended in England in October 1991, and it was finally banned in June 1993.

The tendency to ignore early warnings merges with deliberate suppression of evidence unfavourable to a drug or manipulation of evidence to produce a favourable result. A sin of omission becomes a sin of commission and often a legal offence.

# THE DRUG IS EXCELLENT BUT THE MONKEY DIED: COVER-UP & FRAUD

Scientific method involves a specific series of steps for testing the efficacy and safety of a trial drug. There are many points in this

sequence at which decisions can be made to manipulate the findings to get a result favourable to the drug.<sup>20</sup> Many of the ways of falsifying results fall short of outright fraud: for example, if several scientists produce different readings of a specimen, only the favourable one will be recorded. Toxicological studies are repeated until one favourable to the company is achieved; meanwhile the unfavourable ones are not submitted to the regulatory authority.

Outright fraud may include excising malignant tumours from live animals and continuing the trials - as occurred with Searle's Aldactone or, when cancer is suspected, not testing the tumours at all.

Nader's Health Research Group targeted Searle's Flagyl for suspected carcinogenic properties:

- when two pathology tests conflicted, Searle employees failed to get a third but submitted only the better of the first two;
- Searle employees were unable to explain many of the procedures they used to record, edit or verify microscopic findings;
- the company was unable to account for discrepancies between raw data and final submissions to the FDA.

While the boundaries between fraud, criminal negligence and civil negligence are obviously blurred in some cases, in others it is painfully clear. The FDA denounced Johnson & Johnson's subsidiary, McNeil laboratories, for concealing information on side effects of Flexin which included its association with 15 deaths from liver damage.<sup>21</sup>

The A. H. Robins Company brought more science to manipulation and suppression of evidence in the Dalkon Shield scandal than they had brought to testing the device itself. Misrepresentation and concealment were so effective and complacency so gross, that the Australian Ministry of Health believed that, up to 1974, there were no adverse reports and after that the incidence was 0.05 per cent based on the 147,000 sold in Australia. However, the reported rates did not represent the true annual rates. In the end, Australia had the second largest number of damaged women after the United States.<sup>22</sup>

In an effort to limit the scope of medical debate, Robins held a septic abortion conference in late 1973, neglecting to invite two key doctors who were known to have studied the problem. The debate was managed so effectively that the audience could not decide whether the Shield caused second trimester spontaneous septic abortion although

the dangers of the barbed design and the porous tails had been remarked from beginnings.  $^{\!\!\!\!23}$ 

Eli Lilly's submissions to the FDA on DES omitted much relevant information as to its efficacy as a prophylactic in pregnancy.<sup>24</sup> The major manufacturers of the synthetic hormone also suppressed findings concerning cancer risks: by 1947, their submissions for approval were overlooking the more than 300 studies that had implicated both natural and synthetic oestrogens in human and animal cancers.<sup>25</sup>

Beginning in 1974, a Lilly employee in the UK compiled quarterly summaries of significant adverse reactions there to benoxaprofen. The American company was informed regularly by telex and telephone of adverse reactions and of the reports sent to relevant authorities. None were reported to the FDA.<sup>26</sup>

The concealment story of MER/29 is one of the very few cases where bastardy is redeemed by a modicum of conscience.

In May 1959, a female technician in W. S. Merrell's toxicology laboratory found that two monkeys died and one reacted badly to the trial drug. Refusing to obey orders to smooth out the graph of the sick monkey's weight and to extend the life lines of the others, she went to the Director of the toxicology laboratory, who told her to be quiet. At that time, the cover-up had been going on for at least two years.

Even when the FDA questioned the fraudulent results sent with their application, Merrell stood firm. Challenged on the low margin of safety, a Merrell official specifically stated that there had been no loss of body weight in animals and no untoward blood responses. Despite continuing evidence of damage in beagles and humans, when the FDA demanded more evidence especially on liver damage, the company sent a three page summary of liver studies that 'established beyond reasonable doubt that MER/29 produces no alterations in hepatic (liver) functions in man.' In April 1960, the FDA gave its approval.

The FDA quickly realised that Merrell had been withholding evidence and tried unsuccessfully to instruct them to recall their drug but the coverup began to fail in February 1962, when an FDA inspector met the husband of the woman who had objected to falsifying evidence two years earlier. They made conversation in a car pool ... In April, three FDA officials visited Merrell with a certificate of inspection, found evidence of falsified submissions and pulled MER/29 off the market. Two cheers for law enforcement!<sup>27</sup>

Despite prerelease warnings and early complaints about the nervous system risks of thalidomide, when a Dusseldorf neurologist wrote to Grunenthal, they replied 'Happily, we can tell you that such disadvantageous effects have not been brought to our notice.' This lie was to characterise the whole of their response to the unfolding tragedy. Under pressure, they dropped 'completely' from claims that it was 'completely safe' on the general grounds that no drug is completely safe but did not acknowledge the burgeoning evidence that this particular drug was dangerous beyond anything previously known.

Grunenthal used contacts on a German medical magazine to prevent publication of a paper connecting thalidomide with peripheral neuritis. They also planted pieces: 'Sooner or later we will not be able to stop publication of the side effects of Contergan [thalidomide]. We are therefore anxious to get as many positive pieces to work as possible.' That is, public relations had degenerated into blatant fraud.<sup>28</sup> The thalidomide cover-up was not limited to Germany. Richardson-Merrell presented misleading data on thalidomide to the FDA.

Roche had been aware of potential risk of respiratory arrest with midazolam for three years when it marketed the drug in 1983 as Hypnovel, the last of its benzos. Its very short half-life made it suitable for marketing as an injectable preanesthetic for dental work and uncomfortable diagnostic procedures. Because the procedures were so simple, they would be carried out in premises without resuscitation equipment or appropriately trained staff. Nevertheless, Roche marketed an unnecessarily strong form.

Following two deaths and a great deal of pressure, it released a less concentrated solution for the UK but continued to sell the stronger one in the United States under the name of Versed where had it killed 66 people by  $1988.^{29}$ 

### WHY BOTHER? FAILURE TO TEST

Since there will always be a strong possibility that scientific research may turn up uncongenial results that may have to be concealed or fudged, why bother testing?

Robins did not test the Dalkon Shield before or during marketing or after changes had been made in the composition and design of the product. DES was marketed on unverified and patently suspect claims made by two American practitioners regarding habitual or threatened abortion. A widespread but unfounded belief that the foetus is not susceptible to adverse drug effects made their assertions seem plausible. Sir Edward Charles Dodds, the protagonist in the search for a synthetic oestrogen, prevented the marketing of DES as a contraceptive because he believed that women who used it would later develop cancer. His belief was tragically vindicated thirty years later. The firms that competed to find uses for DES conveniently ignored this and other early evidence. Eventually Eli Lilly would be challenged for not testing DES on pregnant animals before testing it on pregnant women. DES on pregnant animals before testing it on pregnant women.

Richardson-Merrell distributed 2.5 million tablets of Mer/29 in the US, although it was not yet approved. This largesse was presented as part of a testing programme but the doctors were chosen by sales representatives who were instructed not to offer placebos unless doctors asked. The doctors were told that they had been specially selected and that it did not matter very much if they did not keep records of their trials. That is, Richardson-Merrell were not interested in trials but in softening the market for their new miracle product.

When the same company applied for approval to market thalidomide, their pharmacists knew the drug could cross the placenta but failed to conduct animal tests or monitoring of pregnant women to see what it did when it reached the foetus.<sup>33</sup>

This was a fairly straightforward failure to test compared with what had gone on with thalidomide in Germany. Grunenthal's early trials were unsatisfactory because the company relied on testimonials of a startlingly impressionistic kind. One Dr. Jung reported concerning a trial on four youths suffering from moral tension as a result of masturbation. In 1955, when he recommended that the drug was ready to market, he had given thalidomide to twenty patients for only four weeks. Simultaneous with these subservient reports, other trialling doctors were reporting giddiness, nausea, constipation, hangover, wakefulness, and allergic reactions. The drug was launched anyway. The British tests were conducted only after the launch. The drug was launched anyway.

Seen from the standpoint of the researcher, testing anxiolytics for *efficacy* is difficult because the warmth of the doctor increases the efficacy of the drugs he prescribes-the placebo effect.<sup>36</sup> Hence the FDA did not produce testing guidelines for anxiolytics until 1977 - twenty years after meprobamate had inaugurated the era of the tranquilliser. Yet testing for *safety* does not rely on doctor warmth - some things can be done and should be.

As early as 1960, cross-tolerance between chlordiazepoxide and barbiturates and barbiturate-like drugs indicated that the newest drug had the same addiction potential as the older ones.<sup>37</sup> The benzodiazepines were barely tested enough to establish their efficacy and not at all for their safety. Wyeth permitted Ativan/lorazepam to be prescribed for long-term use (more than four months) although it had not been assessed through long-term clinical studies.<sup>38</sup>

One critic pointed out that, when reports began to come in about distress, violence and psychosis associated with Halcion/triazolam, Upjohn questioned trial subjects only about their previous night's sleep thus deflecting reports about rebound anxiety and numerous other symptoms during the day. The firm also funded research into use for one to seven nights that did not address long-term responses.<sup>39</sup>

# OH WELL! INCOMPETENCE, DECEIT & LACK OF QUALITY CONTROL

Where failure to test occurs in the clinical stage of drugs, it is often hard to distinguish between stupidity, incompetence, and greed among doctors and the failure of drug companies to brief them appropriately. At law these failures can all be negligence. Between 1977 and 1980, the FDA discovered at least sixty-two doctors who had submitted manipulated or frankly falsified data.

Dr. Ronald C. Smith, a psychiatrist, was hired by Sandoz, Upjohn, Cyanamid and three other pharmaceutical companies to test at least a dozen psychotropic drugs; only 3 out of 60 patients listed as having been tested by Smith, had actually received the drugs; the way he got his pill count correct was to count how many pills the patient should have taken and flush the rest down the toilet.

Trial doctors get into more strife than Flash Gordon. Dr. James Scheiner had his office vandalised the night before an FDA audit and his studies dumped in a whirlpool bath; at the following audit, his office caught fire; before the reschedule audit, the unfortunate man was mugged in his office. Dr. Francois Savery, who had earned a fortune testing drugs for Hoffman-La Roche and other leading companies, regrettably dropped his data overboard while out in a rowboat; a US court rejected his explanation and sentenced him to five years' probation for felony fraud.<sup>40</sup> Many frauds are undetected by normal inspections. In 1978, when June Froman was admitted to hospital with a dead liver, her physician Dr. Jerome Rotstein was overseas. He had

been monitoring her treatment for arthritis with Pfizer's experimental Sudoxican; Rotstein blamed Pfizer but investigations revealed records of clinical studies stating that her condition was normal up to several days before her hospitalisation; Rotstein had been out of the country and never done any of the studies. Only the patient's timely death alerted the FDA to the fraud.<sup>41</sup> The Dalkon Shield scandal involved breaches of law and regulations at almost every stage, including poor quality control.<sup>42</sup>

### RISKS AND CIRCUMSTANCES: FAILURE TO WARN

Perhaps the most basic rule in the pharmaceutical industry is not to sell something that is known to be dangerous, except under rigorously controlled conditions if the product has some considerable benefit in some circumstances that outweighs its risks. In that case, the risks and circumstances must be clearly spelled out.

In 1978, the Tokyo District Court found Ciba had failed to do this in the case of clioquinol: 'In January 1956, when the defendant companies began manufacturing the clioquinol preparations in question, they were already guilty of not having taken the necessary steps to avoid possibly disastrous results.'<sup>43</sup>

Both the partnership that originated the Dalkon Shield and the company that took it over failed to warn of its dangers and risks.<sup>44</sup> In August 1961, thalidomide was placed on prescription in three German states following complaints about peripheral neuritis. Grunenthal told licensees in Britain, US and Sweden about risks of peripheral neuritis but did not acknowledge the 2,400 cases reported in Germany alone. The parent company urged licensees in developed countries to drop the word 'nontoxic' from its promotions but continued to send promotional literature to West Africa describing thalidomide as 'completely harmless'.<sup>45</sup>

None of my experiences as a benzodiazepine addict was as shocking as the discovery that BZD addiction is an open secret and had been since the drugs first went on sale over thirty years ago.  $^{46}$ 

Roche not only had a venerable tradition of opium dealing between the two world wars - in the more immediate past, it had marketed Noludar/methyprylone, a barbiturate-like drug - that is, a drug potentially capable of causing addiction. In 1956, another barbituratelike drug, meprobamate, appeared and the following year, both drugs were known to be addictive.

No action was taken in the research and development phase or the introductory phase. Exiguous warnings only appeared when the products were already in decline and the public was becoming resentful of iatragenic addiction. This pattern has been repeated on a much greater scale with the benzodiazepines. Perhaps the fact that meprobamate had generated much misery but few law suits encouraged complacency?

Roche had had inside knowledge of dependence/addiction for several generations before it marketed Librium/chlordiazepoxide. The firms which then scrambled to market Me Too drugs without adequate warnings did so in the knowledge that they were following a well marked track.

# NOT EVEN AFTER THE HORSE HAS BOLTED? FAILURE TO RECALL

Rogue drugs remain on the market long after their risks are known. The first strong criticisms of the Dalkon Shield had emerged in 1970. In May 1974, two years after they were first warned about the risks of mid-trimester, spontaneous septic abortion, Robins sent out a 'Dear Dr.' letter advising therapeutic abortion in case of pregnancy. They did not warn of the true risk of pregnancy or why induced abortion might be desirable. The Medical Device Amendments Bill (1976) had been passed as a result of the scandal but it was not until four years later, with the United States Planned Parenthood Federation reporting difficulties at the rate of 26.4 per cent in their clinics, with the FDA requesting suspension of sales, and with lawsuits mounting, that Robins advised the removal of the remaining Shields.

The company was under enormous pressure to recall the Shield; even so, it only recommended the removal of implanted devices, something less than total recall  $^{47}$ 

Merrell resisted FDA efforts to have it recall MER/29 after reports of cataracts; Merrell's position was that the cataract connection was not established whereas the FDA thought the incidence of cataract in MER/29 patients was extremely high. The FDA capitulated, agreeing to a warning letter but since the parties could not agree on its text, no warning was sent.<sup>48</sup>

Grunenthal not only failed to recall thalidomide when it received reports of peripheral neuritis, it actually instructed detectives to investigate the doctors and citizens who called it irresponsible for its failure to recall the drug.<sup>49</sup> If thalidomide had been recalled at this stage, the risks of perinatal death and widespread phocomelia would have been greatly reduced.

After information about Halcion's early trials came out, the United Kingdom authorities instructed the firm to withdraw the drug. When they refused, their license was suspended.<sup>50</sup>

## THE DOLE QUEUES ARE GETTING LONGER. COERCION OF EMPLOYEES

Even salaried employees can imagine impending unemployment more vividly than they can imagine what an eighteen-year-old feels like to lose her vagina and uterus to cancer. They, have difficulty imagining a justice system in which they will be respected and rewarded for speaking out. Investigators, including commercial laboratories, may be pressured into finagling results of drug trials by threat of loss of future work.<sup>51</sup>

IBT pressured an employee who found that rats fed TCC developed testicular lesions. Under pressure from another client, he did not change the findings but did consult with an independent investigator, who agreed with him. Eventually, his boss rewrote his report and, rather than leave the firm, he signed it. Consequently, Monsanto won approval for higher TCC content in deodorant soaps.

Similar deceits occurred in relation to a herbicide and an insecticides Wayne Crowder, a quality control supervisor in the Dalkon Shield manufacturing plant at Richmond, Virginia, complained about wicking - one of many repeated complaints about infection travelling up the tails of the shield into the sterile environment of the womb. He was told that his conscience did not pay his salary and that complaints were insubordinate; if he valued his job he would do as he was told. <sup>53</sup>

In many cases of suppressed evidence, or ignored warnings, the threat is never articulated-merely implied in the power relationship of executives and staff.

#### **SHOW AND TELL: PECUNIARY INTEREST**

Even the most prestigious men may succumb to the temptation of pecuniary interest. George Bush was a member of the board of directors at Ely Lilly before he became part of Reagan administration; he also held \$180,000 worth of stock. When he joined the Reagan team, he tried to get the government to join hands with the drug industry and by mid 1982 his restrictive influence on the policing activities of the FDA was apparent. In the first six months of the fiscal year 1982, there was a 66.4 per cent decrease in total FDA law enforcement actions compared with the interval before the Reagan administration took office. <sup>54</sup>

The US justice Department delayed for three years before moving against Lilly and benoxaprofen-despite mounting public pressure and massive evidence against both the firm and the drug. In August 1985, Lilly pleaded guilty to twenty-five misdemeanour counts of failing to notify the FDA of numerous deaths and injuries among overseas users and was fined \$25,000. The company's chief medical officer pleaded 'no contest' to fifteen misdemeanour counts and was fined \$15,000. According to Russell Mokhiber, there is a strong reek of whitewash in this case. <sup>55</sup>

The FDA was slowed down by Bush's conciliatory policy but it continued to score small victories. Dr. Stanley W. Jacobs, University of Oregon Medical School was hired by Research industries to monitor two safety tests on a new drug for inflammation of the bladder. In 1979, when the FDA investigated irregularities in the data collected, it discovered that Dr. Jacobs held \$600,000 worth of Research industries stock.<sup>56</sup>

Believing that pregnancy is a 'social evil-contributing to poverty, unhappiness and unrest', Hugh J. Davis, assistant professor of obstetrics and gynaecology at Johns Hopkins University, had begun testing the Shield in 1968 on black, Latina, and poor white women in Baltimore. Two years later, Davis, coinventor of the Dalkon Shield, testified to the Senate committee on the alleged dangers of oral contraception that new intra-uterine devices were virtually 100 per cent effective and less risky than orals.

When questioned about commercial interest in such devices, he said 'I hold no recent patent on any intra-uterine device.' Nevertheless, he currently held a 35 per cent interest in the Dalkon corporation.<sup>57</sup>

## QUID CUSTODET? LEGAL CORRUPTION

One of the more refreshing discoveries I have made during my investigations of rogue drugs is that the legal profession is generally more conservative about ethical issues and the implications of white-collar crime than is the medical profession. The Dalkon Shield affair is a shocking exception.

'Dalkon' is an acronym for the three inventors of the Shield: Hugh J. Davis, a gynaecologist, Irwin S. Lerner, an engineer and Robert E. Cohn, a lawyer. From its inception, the Dalkon Shield plan was calculated to dodge legal constraints. When the partnership sold out to A. H. Robins, the company also relied heavily on in-house counsel and externally engaged lawyers to promote favourable data in major journals and at scientific meetings.

On legal advice, the copper content in the device was no longer described as enhancing its efficacy as a contraceptive, but as conducive to radio-opacity, thus keeping it the category of 'device', that was not required to be tested, rather than 'drug', that was subject to more pretesting. (Searle sought approval for its 'Copper 7' on the basis that copper increased efficacy.) A former Robins in-house lawyer testified that Robins had lied to the FDA about this.

Robins apparently told the Australian Federal Department of Health that the copper was antifungal, not contraceptive. Hence, although Australia was requiring testing of devices containing leached copper, the Dalkon Shield 'escaped such scrutiny.'58

In this instance, United States lawyers were clearly telling manufacturers how to conduct a fraud that would have devastating consequences for women. Worse, they compounded their offence after judicial investigations began. During the ten years of intense litigation, the defence lawyers played dirty in court, accusing women plaintiffs of self-infection by promiscuity. The lawyers lied. They avoided discovery of relevant documents by invoking lawyer/client confidentiality. They destroyed documents.

When a trial judge, who had constantly resisted these tactics, accused the company of 'corporate irresponsibility at its meanest', they retaliated by appealing on the grounds of abuse of judicial discretion and power and sought to have the judge removed from the bench.<sup>59</sup>

It was this phase of the scandal that resulted in the Medical Device Amendments Bill 1976 requiring more careful testing of devices (as distinct from drugs). Judgements against Robins continued and the company filed for bankruptcy August 1985. Its losses in damages and punitive payments are likely to be one billion dollars by the year 2002.

### **GREASE AND VARIANCE? IT'S All BRIBERY!**

The amiable custom of grease and variance payments that may be counted as marketing by other means, looks suspect when scrutinised in the context of white-collar crime. Some cultures use bribery as a sort of informal taxation but in the industrialised nations, it becomes a way criminogenic industries fight back against regulatory agencies.<sup>61</sup>

The US Securities and Exchange Commission disclosures of questionable payments consistently show the pharmaceutical industry at or near the top of the bribery scale - 19 of 20 US companies with the highest worldwide sales of pharmaceutical goods disclosed substantial questionable payments. And these payments are consistently underestimated. Fortunately, they are also consistently revealed.

Bribes for registration of approval for sale and bribes for permission to market are serious-even when they are not direct. 'Almost every type of person who can affect the interests of the industry has been the subject of bribes by pharmaceutical companies: doctors, hospital administrators, cabinet ministers, health inspectors, customs officer, tax assessors, drug registration officials, factory inspectors, pricing officials and political parties.'<sup>63</sup>

Doctors are no more resistant to bribes than they are to inducements. Indirectness may permit them to pretend that they are not at fault: a letter to Dr. Nelson Cantwell of Merck begins by thanking him for suggesting a grant for the ----- university rheumatology section and then reports that the writer will use a method of investigation that masks the side effects of indomethacin.<sup>64</sup>

Bribes can be used in cover-ups. Some experts testifying before the many hearings on the Shield received payments from Robins while requests from independent researchers for funding were rejected. Grunenthal also resorted to bribery when they could no longer deflect criticism over thalidomide. 66

Despite the harm done by rogue drugs and the lawbreaking revealed, drug cases are rarely the subject of criminal action. The involuntary manslaughter charges against executives of Grunenthal concerning suppression of dangerous effects of thalidomide is exceptional. Whatever happened to the rule of law? The overarching explanation is that law is often rendered nugatory by the medical-industrial complex whether the offence is homicide or bribery.

### IN BED TOGETHER: THE MEDICAL-INDUSTRIAL COMPLEX

Comparing the roles of the various professionals in the rogue drug scandals, one begins to perceive the existence of an unwholesome nexus between the medical profession and the drug companies. At the very least, inept doctors rely on detailers to keep them (mis)informed. They would probably baulk at lending their names to a corporation executive for use over a fraudulent paper but their very inertia allows the drug houses to take credibility from the association of pharmaceuticals and doctoring.

Addressing the drug company executives who constitute the Pharmaceutical Manufacturers Association, Dr. James Goddard, then head of the FDA, said that Mer/29 was not an isolated case – 'I have been shocked at the materials that come to us. I have been shocked at the clear attempts to slip something by us. I am deeply disturbed at the constant, direct, personal pressure some industry representatives have placed on our people.' That was in 1966. What offended Dr. Goddard amounts to an industry belief in a divine right to flout authority and avoid responsibility.

The belief derives from vestigial laissez faire capitalism, aggravated in the US at least - by corresponding attitudes in government. The Reagan administration abandoned a plan initiated under President Jimmy Carter for patient package inserts for prescription drugs. <sup>69</sup> As Reagan's Vice President, George Bush headed the Task Force for Regulatory Relief.

The nexus between manufacturers and government is strengthened, even made possible, by that other nexus between manufacturers and the medical profession. Together, they constitute a medical-industrial complex. 'The AMA (American Medical Association) and PMA (Pharmaceutical Manufacturers Association) and their equivalents in other countries, are firmly linked with the medical-industrial complex. The two associations almost invariable support each

other before committees of enquiry, and provide mutual aid for lobbying efforts in the capitals of the world.' The PMA gets allegedly independent medical support and the AMA gets cash, most visibly through advertising in its publications.<sup>70</sup>

A comparable - and no less dangerous - symbiosis exists between universities and industry. If the pharmaceutical industry controls the postgraduate education of doctors in prescribing through advertisements and detailers, some may escape because they are resistant to blandishment or prefer to use professional information sources. If undergraduate education is infiltrated, few will escape.

Exchange of personnel is a characteristic of the medical-industrial nexus. Both the medical publication business and the drug industry gain credibility from the presence of duly qualified doctors on the payroll. If these doctors can be seduced from the regulatory arm, they may even teach corporations how better to circumvent the law.

The FDA approved the use of DES by pregnant women in 1947, when Dr. Theodor Klump was head of its Drug Division and instrumental in getting the drug approved for marketing. At that time, the FDA did no testing of its own, relying on drug company research. The drug companies had not tested DES on pregnant animals before they sold it for use by pregnant women.

In his FDA job, Dr. Klump earned \$6,000 p.a.; when he left to become president of Winthrop Laboratories, a company that had filed for DES approval, his salary jumped to \$30,000. Indeed, several key figures in the approval of DES found jobs in the pharmaceutical industry and Klump is suspected of swinging the American Medical Association from a critical to a supportive stance on DES.<sup>72</sup>

The radical new version of the British National Formulary, launched in 1981, was designed by a Joint Formulary Committee of the British Medical Association and the Pharmaceutical Society of Great Britain as a concise, basic drug-prescribing guide to keep doctors up to date. Dr. Frank Wells, from the staff of the BMA, was the doctors' representative on the committee while Dr. John Griffin represented the Department of Health. Dr. Griffin became Director of the Association of the British Pharmaceutical industry in 1984, later appointing Wells as Medical Director. When the National Health Scheme launched its Limited List in 1984, excluding about 1800 preparations from government subsidy, it contained a lot of preparations criticsed by the BNF: antacids, cough mixtures, minor painkillers - and most of the benzodiazepines.

The ABPI responded with a virulent attack that was inconsistent with Dr. Griffin's views when he had been with the Department of Health. You will meet Dr. Wells elsewhere in this book as spokesman for the ABPI and the author of some comfortable views on benzodiazepines. Doctors may provide connective tissue for the medical-industrial complex without anything so crass as jobs for favours. Their role as middlemen in drug marketing is undignified but hardly unlawful or even unethical. Codes of ethics are inevitably motherhood statements whose main value is soothing. They bear little relation to actuality and are sometimes manifestly contradictory.

The (Australian) National Medical Media Council (NMMC) submission to the House of Representatives Drug Inquiry is superficially a getting to-know-you exercise but its active agenda is to oppose any reduction in or restraint on advertising in medical journals.

In order to take the sting out of consumer group criticism of advertising, the NMMC describes it as only one influence on doctors among many. Then, to further defend advertising, medical publications and the drug houses, the Council inflates its influence as a source of important information.

None of the Council's fifteen member publications relies solely on direct subscriptions. The Council makes some dramatic admissions: 'Virtually the whole of the advertising revenue derived by medical journals comes from the pharmaceutical manufacturing industry ... Pharmaceutical advertising accounted for virtually all of the \$18.7 million gross advertising revenue earned last year [1989] by medical publications . . .'<sup>77</sup>

How are we to interpret Clause 3 of the NMMC Code of Business Ethics in view of these admissions? Clause 3 says they will 'maintain absolute editorial independence from advertisers . . .' $^{78}$ 

Is it possible to maintain independence from the organisations that pay for medical publications and guarantee the livelihood of their publishers?

Clause 5 of the NMMC Code reads 'to refuse knowingly to accept advertising which is untruthful, misleading, deceptive . . .' - and most of its member publications adopt a similar clause. The word 'knowingly' is less a loophole than a bolthole. It could justify advertisements for any of the rogue drugs - and from time to time, it has.

The histories of the rogue drugs are not replete with rigorous surveys or exposes published by the medical journals - despite the motherhood clauses in their charters about maintaining editorial publishing misleading advertisements. independence and not Occasionally, the contradiction between the financial need to accept advertising and ethical obligation to tell the truth becomes visible. Interrogations in the 1973 Senate Subcommittee on Health revealed that JAMA (Journal of the American Medical Association) continued to publish advertisements encouraging the promiscuous use of the highly dangerous Parke Davis antibiotic, Chloromycetin, well after editorial comment had acknowledged its risks.<sup>79</sup>

The conflict in medical publications is made possible by two sets of attitudes in the profession itself - those who prefer professional sources of information and prescribe cautiously and those prefer commercial sources and prescribe irrationally. A 1972 study concludes that the medical profession contains 'rather diverse philosophies of medication'. One of those philosophies is more compatible with the marketing ethos than with medical ethics.

Although governments are somewhat coy about intervening in highly profitable industries, the industries are not at all coy about intervening in government. Hence, there tends to be a weakness in regulatory authorities even when they are not subjected to the all-out war that we see in the USA. The Dalkon Shield confrontation revealed the FDA to be not inactive but a bit weak.

In Australia, the division of responsibility between the Commonwealth, which is responsible for regulating imports of therapeutic goods, and the states, which apply standards, invites drug houses to play the centre against the peripheries.<sup>81</sup> In Australia, as in the USA, corporate crime in the pharmaceutical industry dodges the rule of law.

## UNEQUAL BEFORE THE LAW: FAILURE TO PUNISH OR COMPENSATE

The human tragedies of rogue drugs lack closure: manufacturers are not often punished and if punished, the penalties are hardly ever severe. Doctors and manufacturers are rarely found in jail.

DES, the first synthetic oestrogen, was synthesized in 1938 but not patented. The drug companies competed with each other to register

uses for it - including some indications for postmenopausal women. The most common use was for threatened miscarriage. The majority of girls born to DES-treated mothers had genital abnormalities including one in one thousand with cancer while boys also had serious problems with deformed genitalia. The drug was withdrawn for prenatal use in 1972, following an extraordinary saga of regulatory failure.

The first legal victory was won by a girl who lost her womb and vagina at the age of eighteen. Although no fewer than 500,000 people were exposed to the drug in the USA, there were only 6,000 plaintiffs against various companies in 40 American states, some of whom received awards exceeding \$1 million.<sup>82</sup>

Some received nothing; some did not sue. Many DES daughters could not sue because they were unable to establish the particular brand of the drug their mothers took. Others were prevented from suing by the provisions of the statute of limitations in their states. Still others could not get the records of their mother's treatment. The lawsuits did, however, encourage Eli Lilly, the major manufacturer of DES, to discontinue its postcoital contraceptive pack in 1974 and notify 300,000 physicians that it recommended against this use of the drug.<sup>83</sup>

The discrepancy between personal injury and legal consequences in the case of MER/29 were less dramatic. Two years after Merrell's technician found the dead monkeys, Merck tested Merrell's anticholesterol drug against its own and found that dogs and rats went blind on MER/29. Complaints were staved off by persistent manipulation of evidence, fraudulent submissions to the FDA, and refusal to provide samples to independent testers before the drug was recalled.

In 1963, a Federal Grand jury handed down a twelve count indictment against Merrell, its parent company, Richardson-Merrell, and three of its employees, who were charged with knowingly making false, fictitious and fraudulent statements to FDA The defendants pleaded 'no contest' which is tantamount to a plea of guilty and were sentenced to six months probation. The company was fined a total of \$80,000 although the after tax profits for MER/29 in 1960-61 were over \$1 million.

The tort cases, 95 per cent of which were settled between 1962 and 1967, were somewhat more punitive. Some of the victims took legal action and succeeded: a New York jury awarded one young woman \$1.2 million including \$850,000 to punish the company but this was reduced

to \$100,000 by the judge. But few of the 5,000 known victims sought legal redress.<sup>84</sup>

The criminal law is not always exercised to its fullest. Oraflex victims might die of liver failure, kidney failure or massive haemorrhage and heart failure. And at least one hundred and twenty-two did. Thousands of others survived with damaged livers.

By late July 1982, pressure for action against Eli Lilly's highly promoted drug was mounting. When the British government suspended sales of Orpren in August 1982, Lilly voluntarily withdrew Oraflex as a better public relations move than waiting for an order to do so. Despite evidence that Lilly had released the drug in America while knowing about deaths in Europe, the FDA rejected a recommendation to prosecute.

This may or may not have had something to do with the conciliatory activities of George Bush.

More than one hundred negligence suits were brought and in 1983, \$6 million in punitive damages were awarded against Lilly for benoxaprofen deaths. Two years later, Lilly pleaded guilty to twenty-five misdemeanour counts of failing to notify the FDA of numerous deaths and injuries among overseas users and was fined \$25,000. The company's chief medical officer pleaded 'no contest' to fifteen misdemeanour counts and was fined \$15,000.

Selacryn, Smithkline's pill for high blood pressure, was harsh enough taken in the recommended dose for five months to destroy 98 per cent of the liver of an otherwise healthy 34-year-old woman. Her blood pressure had not even been excessively high. Her husband and two young children accepted \$350 000. No fewer than sixty users died and over five hundred survived with liver damage.

In 1984, the Justice Department charged Smithkline and three of its officers with thirty-four counts related to the drug. Smithkline, pleading guilty to all charges, was fined \$100,000. The company's executives were put on probation and sentenced to two hundred hours of community service.

During the 1980s, many Selacryn victims or their survivors sued and the manufacturer settled all but 13 of 100 or so cases. Senator Howard Metzenbaum said that the Reagan administration had 'let down the American people.' Considering the thirty-six deaths involved,

Smithkline should have been charged with felonies and not misdemeanours. The FDA had specifically recommended felony charges but the justice Department had overruled it.<sup>86</sup>

Grunenthal played off the threat of court proceedings against the desirability of providing for the children promptly in an out-of-court settlement. After a trial lasting two years, proceedings were dropped in 1970 in exchange for \$31 million. The German Government added an additional \$15 - \$20 million to Grunenthal's contribution. Apparently no thalidomide case was ever decided in court, nor is the full payment known - most companies asked for secrecy in their settlements to divide the plaintiffs from one another and keep the demands low.<sup>87</sup>

Distillers, although no more innocent than Grunenthal, was particularly resistant to acknowledging responsibility. In 1971, Distillers' pre-tax profits totalled £64million on assets worth £421 million. Two years later, after a massive public campaign, this licensee agreed to pay £2 million a year for 10 years into a trust to care for four hundred and thirty British thalidomide children.  $^{88}$ 

Upjohn's Halcion/triazolam was one of the first benzodiazepines to attract significant litigation. Trials in The Netherlands were bedevilled by failure to discriminate between long-acting benzodiazepines and short-acting; the fact that long-acting formulae cause fewer withdrawal symptoms is no guide to whether the effects of the latter wiII be benign or virulent; short-acting BZDs have less margin for missing a pill before withdrawal symptoms set in and the symptoms themselves are more cruel. However, the interim verdict was that Halcion in high doses could be dangerous.<sup>89</sup>

This drug is also the subject of suits in the USA and UK where complainants refer to severe convulsions, psychosis, and violently destructive conduct as results of addiction. One US case was settled out of court, allegedly for six million dollars.<sup>90</sup>

The only Australian BZD case concluded to date involved Lexotan/bromazepam. The patient, a 36-year-old working mother, had taken the drug for three months under the supervision of a psychiatrist who prescribed forty-eight milligrams daily when the recommended maximum dose was eighteen.

Her health deteriorated from a state of simple tiredness and environmental stress, uncomplicated by pathology, to iatragenic anxiety, hallucinations, and the usual benzodiazepine symptoms. When she was admitted to hospital for a broken elbow, and taken off the pills, she suffered several grand mal seizures that were observed and recorded by her attendants. After a harrowing withdrawal experience, she successfully sued the psychiatrist and settled for almost twenty thousand dollars. 91

Only a small proportion of victims ever sue because, in most jurisdictions, individual law suits against companies are too expensive for the average victim. Many victims do not go to court because they are simply too ill and depleted to face the brutality of the system.

Complainants suing under British law have the additional obstacle that class actions are not part of that system. In England, the Benzodiazepine Solicitors' Group found an answer to the lack of procedures for class action by winning permission to run a test case that is taken to be representative of the others. Over three thousand consumers are suing Wyeth in respect of Ativan in an action that is largely funded by legal aid.

The future of the action is thus tied to the availability of tax dollars to fund legal aid and the policy in disbursing them.

Rogue drug tragedies do not represent isolated and random misfortune. They represent the predictable outcomes of blameworthy behaviour. But the mechanisms of justice are inadequate in these cases. Company executives and doctors are rarely charged, tried or punished. Patients are rarely compensated. Perpetrators and survivors are unequal before the law.

# CHAPTER 6 THE RULE OF LAW

I have no gun, but I can spit.

W. H. Auden

#### **GETTING AWAY WITH MURDER**

Corporate crime in the pharmaceutical industry is a type of gallows comedy: organisations that represent the acme of twentieth century marketing so far as planning and control are concerned behave like nineteenth century enemies of the people over safety regulations. Their confreres in the medical wing of the complex are unwilling or unable to see how they are being used. And most legislatures are slow to confront the difficulties inherent in policing this mode of crime.

Our understanding of atrocities like thalidomide, and thus our capacity to prevent their recurrence, is bedevilled by failure to examine the relationship between the pharmaceutical giants and the medical profession. Both Braithwaite and Mokhiber, for example, recognise that unwholesome doctors collude in fraudulent drug trials, that apparently decent doctors are vulnerable to advertising, promotions and detailers, and that the profession as a whole is not much concerned with adverse drug reactions. They fail to consider doctors as free agents and active participants in the medical-industrial complex. Patients are consumers of pharmaceuticals in the sense of being the end-users but, from the viewpoint of marketers, doctors are the ones who must be sold prescription drugs. Pharmaceutical advertising and promotions are directed at doctors.

Pharmaceutical crime must be seen as including offences related to production and offences related to distribution-in other words, the offences of corporate criminals and the offences of their medical accomplices. The offences of each wing require different remedies because complicated problems are rarely solved by concentrating on a single solution. Corporate crime in the medical-industrial complex is so securely embedded in our culture that it is almost taken for granted so it must be tackled-on both sides of the complex-with every available resource.

Pharmaceutical marketing is essentially a planned process, requiring extensive control and predictability: research and development, manufacture, promotion and distribution must all be

budgeted against anticipated profits. Costs need not be minimised nor profits maximised to achieve marketing success but they must be known or capable of being predicted over a given time span. Multinational operations permit both the rationalisation of prices across many countries and discreet tax avoidance. The most effective way to achieve the degree of stability needed for successful planning is to control as many factors as possible doctors no less than raw materials.

The multinationals do not need to enter conspiracies to do this. They are able to influence costs, and secure the acquiescence of the medical profession and government simply because the size of their presence exerts a pervasive and inescapable influence on the economies in which they exist-rather as a large mountain range determines the weather in its surroundings or a giant tree dictates the ecology of plants and creatures within the radius of its shadow. However, should government move actively to regulate the drug industry, industry actively retaliates.

According to John Braithwaite, American resistance to regulation is organised on a subcultural basis not found in Japan, Britain, Australia or Sweden. 'This is not to suggest that regulatory agencies do not frequently encounter vigorous and effective resistance from business in these countries; it is just to say that they rarely confront the organised subculture of resistance evident in many sectors of American industry.'<sup>2</sup> When judge Miles Lord rebuked Robins's executives over the Dalkon Shield, the company lawyers tried to have him sanctioned and his remarks expunged from the court record.<sup>3</sup> Richardson-Merrell used all the political pressure it could to get thalidomide approved in the US, even to accusing Dr. Kelsey of libel.<sup>4</sup>

Yet dirty fighting is obviously not confined to the United States. In the German trial of thalidomide, the prosecution complained that Grunenthal had menaced five journalists who had written stories that the company disapproved of Grunenthal also hired a private detective to investigate doctors and patients who complained of its failure to withdraw the drug from sale. Dr. John Griffin, Director of the Association of the British Pharmaceutical Industry, commenting on letters of intimidation sent by pharmaceutical companies to doctors who reported adverse drug reactions, reportedly said 'harassment does occur. We ate fooling ourselves if we believe that it does not.'

The derisory outcomes in most cases against rogue drugs reflect the many problems in enforcing laws that often were weak to begin with. Judicially processed cases rarely lead to severe punishment because even if corporate crime can be brought to court, and a conviction achieved, it is difficult to find an effective sanction.

Fines, one traditional punishment for law-breakers, tend not to be paid by companies or to be derisory in relation to profits. Fines are so little deterrent that Braithwaite calls them 'license fees to break the law.<sup>7</sup> There is a double-bind about fines as sanctions because the amount paid is more than offset by the profits made through committing the offence but a series of deterrent fines might exceed the company's assets. Where a great many civil actions are won against a company - as occurred with A. H. Robins - the combination of exemplary awards and repeated punishments for numerous injuries deriving from the same offence may be enough to cause bankruptcy and spoil the chances of latecomers to the justice system. Furthermore, adds Mokhiber, they are discriminatory: 'the current system of jail for street thugs and speeches for corporate thugs creates an inequality of justice that undermines respect for the law.<sup>8</sup>

When executives come to court, judges may be reluctant to send them to prison because they do not fit the criminal stereotype or may even come from the same social stratum as the judge himself. At its most primitive, class sympathy makes judges feel uneasy about sentencing individuals of approximately their own kind.

This uneasiness may be rationalised in a number of ways. It may seem wasteful to jail an executive who is leading an otherwise decent and constructive life and deprive society of his services. It may seem ineffectual to jail a person who may perhaps not learn anything from the experience. There may be fear of setting a precedent - if all white-collar criminals were jailed, which would run society?

Anyway, pharmaceutical killers are rarely charged with any offence, almost never with murder, and never go to jail. The public prosecutor of Aachen, who indicted nine Grunenthal executives in 1965-67 for intent to commit bodily harm and involuntary manslaughter in relation to thalidomide, set an unpopular - and overlooked - precedent.

The resolution of the Japanese cases against Ciba over SMON is better than most. The drug's withdrawal in Japan during September 1970 led to suits against the drug companies and the Japanese government for failing to protect the public. In 1978, the Tokyo District Court found 'the cause of SMON is clioquinol.' By May 1981, of a total 10,000 users affected in Japan, 5,309 had sued and 4,734 received \$490 million; other cases were settled elsewhere.<sup>10</sup>

But victories in particular cases tend to obscure the fact that most of the victims do not sue, not all those who sue, win their cases, and many of those who sue and win receive inadequate compensation. In 1976, a misconceived US immunisation program to prevent a swine flu epidemic that few seriously expected would occur, produced numerous harms, including at least 1,000 cases of Guillain-Barre syndrome, a crippling and potentially lethal viral disorder of the nervous system. The total damages claimed for the 1,600 suits lodged exceeded \$2.2 billion. The hearings had not been completed after more than a decade and the federal government had won eight out of ten cases.<sup>11</sup>

DES has perhaps been the most hard-fought of the rogue drug litigations due to the value of the agricultural market for hormonal meat fatteners. In the true spirit of pharmaceutical marketing, what is lost on the swings of regulation is gained on the roundabout of diversification even when the potential outcomes of accumulating oestrogens may be precocious puberty in children fed too often on fattened meat. DES remains in use.

Prenatal exposure cases illustrate a significant problem with product liability: an increasing disjunction between legal doctrine and current scientific knowledge. A law that developed in relation to immediate risks is too limited for cases of a toxic time bomb that could explode thirteen to twenty-five years after the offence. Where the outcomes of a rogue drug, or some other product such as Agent Orange, asbestos and vinyl chloride, may not manifest until a considerable time after its first use, the difficulties in collecting evidence and prosecuting a case are considerable.

Money is crucial to the decision to sue a corporation. Regrettably, at the time of writing, Australian BZD plaintiffs have not been granted legal aid for a test case similar to the strategy in Britain. Initially, Australian actions were complicated by the division of funding between States and Commonwealth. Then funds became straitened due to the recession and by 1992 potential complainants had not yet formed a plausible political presence to plead the right of product liability cases to funding.

In Autumn 1992, the loose group of Australian solicitors handling benzodiazepine cases were asking for one-off funding on the precedent of the 1991 grant to consumer groups to fight the passive smoking case against the Tobacco Institute of Australia. Potential defendants responded almost immediately with a delicately worded threat to spin

the proceedings out and bankrupt the legal aid system.<sup>13</sup> Multinationals are rich enough to intimidate government as well as individual plaintiffs.

The United Kingdom case against Valium has been withdrawn because the Legal Aid Board considered that the expense involved and the difficulties of the case do not warrant further public expenditure. However, legal aid has now been granted to Halcion victims to pursue claims.

American courts have attempted to devise suitable punishments for white-collar criminals, including such novel penalties as giving speeches about their violations to business and civic groups and making a community service film about their violation<sup>14</sup> but these remedies attempt to make the punishment fit the criminal, not the crime. More telling solutions to corporate crime can be derived from the offences themselves - like Russell Mokhiber's `A 50-Point Law-and-Order Program to Curb Corporate Crime'. <sup>15</sup>

Between 1980 and 1986, courts in five American states adopted a truly innovative theory called 'market-share liability' that permitted the major manufacturers of DES to be sued jointly, with damages being apportioned according to each company's market share at the time the injury occurred. Both manufacturers and insurers have opposed this development but, so far, consumer and survivor organisations have frustrated their attempts to undermine it.<sup>16</sup>

This solution meets the problem of compensating many victims for what is, effectively, a single original offence. It could be applied to any of the Me Too drugs and could greatly simplify the coming wave of benzodiazepine litigation.

The attempt to punish the wrongdoer and compensate the victim in the one process does not work effectively in corporate crime. The experiences of New Zealand and Sweden suggest that, under certain conditions, government-funded no-fault insurance can be both more equitable and also more efficient than tort litigation.

The Japanese system of compensation for pollution-related health injury could be taken as a model for compensating drug-induced injury. Government indemnity assumes the problem of burdens of proof and relieves individuals of private challenges. Firms are charged pollution levies that pay for the scheme and give an incentive to reduce pollution. It is also more effective than tort law.<sup>17</sup>

By now it should be clear that any drug approved for release must be considered experimental until widespread real-life use has revealed its dangers. Corporations keep drugs on the market well after evidence of their unwanted effects have become public and regulatory authorities are reluctant to impose recalls even when they have the power. Doctors do not care to participate in post marketing surveillance. It seems preferable to strengthen security measures before release rather than squabble while end-users die.

Drugs should have a provisional license for the first twelve months on the market-comparable to the P-license for first-time car drivers. During this time, proceeds from sales must go into escrow against harms to trial users. At the end of this probationary period, if no harms have been discovered, the profits, less administrative costs, should flow to the companies.

Instead of concealing potential unwanted effects of new drugs, doctors should explain the P-license and elicit the patient's informed choice between new and older drugs. If patients opt for better-proven drugs, that must be their right. Immediate profits might be reduced by this procedure although adventurous souls might be willing to participate in these first year trials and contribute their own observations concerning adverse drug reactions.

Enabling the patient to become part of the trial team might correct the medical profession's notorious laxity about adverse reactions, preventing the complex from keeping them secret. The drugs' long-term survival in the market - assuming that it has anything at all to recommend it - would be considerably enhanced. All being well, corporations could then budget for a somewhat later peak in the product life cycle of new drugs.

From the survivors' viewpoint, it would be better if injuries never happened than if they did happen and were compensated, so it is preferable to focus on prevention before punishment.

Tinkering with existing laws and regulatory controls is useful but only imaginative and daring responses will raise the drug industry's sense of social responsibility to the sophisticated level of its marketing. Currently, it is like a vehicle with a powerful engine but weak brakes. The vehicle needs to be redesigned.

### REHABILITATING THE CORPORATION

Corporate criminals differ from street criminals: the former can only commit their offences where their employment provides an environment favourable to crime. As Mokhiber shrewdly notes, top management asks for increased profits but lower management commits violations.<sup>18</sup> It follows from this that the corporation must be rehabilitated, rather than the employee - which is not so difficult as it first seems.

Changing individuals has proved to be impossibly difficult but reorganising a corporation's standard operating procedures is not. The fact that corporations depend upon the state for their legal existence puts them within the reach of company law that could be used far more ingeniously than it is at present.

In the United States, for example, courts could order firms to cease operating in areas where they have transgressed repeatedly or could dissolve the corporate entity.<sup>19</sup>

Freedom of information begins with the corporation: all companies could be encouraged to improve internal audits.<sup>20</sup> Most commentators agree that corporate responsibility is diffused when outsiders look for it but localised for internal purposes. An outsider may have difficulty identifying the person responsible for the decision to market thalidomide despite research reports into its dangers but the company knows who makes decisions: they know whom to sack if they need to.

Companies may also devise ways of keeping records that either pinpoint guilt or conceal it. Letting light into the corporate structure is not simply a matter of apportioning blame. Government inspections identify problems, internal inspections identify responsibilities and that can lead to negotiated solutions.<sup>21</sup> Companies may benefit from improving the functioning of internal auditors since they cannot work if concision prevents overall efficiency.

Corporate crime need not be a result of *men's era* anywhere in the organisation but simply of structural blind spots. Braithwaite describes it like this:

organizational crime is often made possible by structures that enable one part of the organization to be wilfully blind to exploitative conduct in another part ... Thus, a pharmaceutical industry quality control manager can do a magnificent job in ensuring that drugs which have been fraudulently tested, and which are being promoted for inappropriate uses, are produced exactly to specifications without feeling a concern for the social irresponsibility of the total process of producing the drug.

Some companies expect middle management to protect top management from knowledge of wrongdoing such as the failure to destroy impure drugs. Therefore, breaking down compartmentalisation should let in light. 'A policy solution is to require by law all reports of the quality control director to be in writing and all decisions to overrule a recommendation of the quality control director to be also issued in writing over the signature of the chief executive.'<sup>22</sup>

Freedom of information should also apply to regulatory bodies everywhere with, of course, inbuilt protection against the commercial use of the information to pirate commercially useful innovations.<sup>23</sup>

The Nuremberg trials led to the formulation of principles concerning the individual's right and duty to refuse to obey immoral orders within an institution. These principles should be invoked to protect employees in the drug industry against frank instructions or oblique pressure to commit offences against law or ethics.

Corporations must give their scientists at least the same freedoms as academic researchers. Indeed, scientists could justifiably claim that drug companies who restrict their capacity to pursue professions according to the accepted rules, are denying them their right to intellectual property in their work. Company officers should retain the right to publish their own research promptly.

There are precedents for this: Grunenwald tried to prevent Distillers publishing Dr. Somers' research into thalidomide and pregnant rabbits during February-March 1962 but he went ahead and published in April. American Schering gives its scientists this contractual right as a matter of course. Extending the traditional academic right of publication to company scientists could perhaps offset the co-option of academic scientists by the drug companies.

The law should protect whistleblowers in both industry and academia by outlawing job blackmail and make honesty easier, for example, by requiring corporations to have an ombudsman or ethics committee who would investigate illegal practices that employees have reported to their boss, but that their boss has decided to sit on.<sup>25</sup> Exxon, for example, requires employees who suspect illegality anywhere to report it to the firm's law Department. Thus, individuals are no longer able to use organisational complexity to protect them from their own consciences. The histories of the rogue drugs reveal many more

instances of management making reckless and criminal decisions than of employees speaking out.

Employees can imagine being sacked more easily than they can imagine being respected and rewarded for speaking out. The ethical corporation is an environment that is yet to be created. And it seems that academia has been corrupted by the large rewards available through industry.<sup>26</sup>

To give the informed public a few clues as to possible bias in apparently bona fide research, all medical journals should require contributors to disclose the source of their research funding. Registration of company names should include information about sources of capital so that trusts cannot be used for public relations purposes as the Wilson ('Feminine Forever') Research Foundation fronted for Searle, Ayerst and Upjohn, or as the Information Centre on the Mature Woman fronted for Ayerst's Premarin.<sup>27</sup>

It takes one to know one ... and you can set one to catch one ... Merck tested Merrell's MER/29 against its own anticholesterol drug, and found that its dogs developed cataracts and several rats went blind.<sup>28</sup> This application of the principle of competition in a free market provided useful ammunition against MER/29. When a firm applies to have a drug approved for sale, it should be obliged to make samples available for testing by rivals.

# **WOOING THE DOCTORS**

Since doctors are the true consumers in marketing terms, the nexus between them and the drug houses needs to be opened up. Some very small changes could result in large gains.

There is considerable evidence that much of the complex does not regard clinical trials as a scientific exercise but as the first softening up of the distributing doctors for the opening sales. Certain corporations are not open to the possibility of adverse reactions and are not prepared to back off their marketing timetables to assimilate negative reports. This tendency is exacerbated by pharmacological ignorance among doctors. Medicine has the aura of being scientific because the discoveries of science are available for doctors to apply but they rarely apply the principles of scepticism and tentativeness that distinguish scientific from technological thinking.

Doctors are accorded the kudos of science but rather few have even a theoretical understanding of research, fewer have actual experience and the remainder do not habitually read research reports with critical acuity - or at all. When drug companies invite them to participate in some poorly designed and ill-supervised charade, most of them are in no position to discriminate between a trial and a market softener.

The Doctor's Reform Society reported a nice instance to the House of Representatives Inquiry into Prescription Drugs (the House Inquiry):

[Squibb] gave everyone a free computer, and that payola went up according to the cost of the product ... They wanted to get it right into the market and they had the great idea to give everyone a free computer. They said, 'We are going to survey our drug and you can put all your results into the computer'. So we all got a computer and a printer and a monitor ... They said 'We are getting these computers back', but last year they sent out the letter saying 'Please sign this release and you can keep the computer'.<sup>29</sup>

There is some evidence that in America, at least, doctors do not take trials any more seriously than drug houses do. An FDA study showed that one fifth of doctors involved in field research for drug companies invented the data they sent to drug companies and pocketed the fees.<sup>30</sup>

This may explain how Richardson-Merrell was able to distribute 2.5 million thalidomide tablets to 1,267 doctors who gave them to 20,000 patients - including an unknown number of pregnant women, although the drug was never approved in the United States.<sup>31</sup> At least ten thalidomide children were born in the US, but trial doctors were not conspicuous in moves to stop the registration of the drug.

Unwanted effects are grossly under-reported, even in a country with a well-developed monitoring system like the UK. A study by the Association of the British Pharmaceutical Industry's 'Centre for Medicines Research' examined the adverse drug reporting activities of one hundred British GPS from twenty-eight practices for one month covering 36,470 consultations and more than 20,500 prescriptions. Six hundred and thirty-eight side effects were observed in 1.7 per cent of consultations and details of five hundred and seventy-six were recorded in the study.

Despite the fact that the doctors knew they were being observed, only six per cent of events were reported to the official adverse reactions monitoring scheme. There is considerable under-reporting even of severe side effects.<sup>32</sup> In other words, doctors generally are not

acting as the watchdogs of public health but as the lap-dogs of the drug trade. The minority who do report may be deterred by harassment from the industry.

Dr. Bill Inman, who set up Britain's Yellow Card ADR reporting scheme, attributes low response to seven deadly sins:

- 1. complacency: the belief that only safe drugs are allowed on sale
- 2. *fear:* of involvement in litigation
- 3. *guilt:* over harm to the patient
- 4. ambition: to collect a run of cases and write them up
- 5. *ignorance:* of the reporting requirements
- 6. diffidence: unsure of own judgement
- 7. *lethargy:* no time, no cards, no concem.<sup>33</sup>

The pattern of reporting also implies a bellwether factor: once a couple of reports appear, others follow rapidly.<sup>34</sup>

The excuse that medical practitioners are too overworked to report ADRs can hardly be invoked: unwanted effects are medical problems as much as any other symptom. If a doctor is too overworked to pay attention to unwanted drug effects, how can s/he pay attention to any symptom at all? There may be other factors than pressure of work: perhaps a uniquely developed resistance to any form of professional surveillance-even though their personal performance is not at issue. Computer databases should give a nice technological veneer to bureaucracy and may increase doctor compliance with requests for information on unwanted effects.

Given the neglect of pharmacology, at least in Australian medical schools, one cannot rule out the possibility that doctors do not understand the significance of unwanted effects. Many symptoms may appear trivial but are significant clues in the great detective story that is diagnosis. Watering eyes and scaly skin, commonplace enough in general practice, may be precursors of cataract and blindness if the patient is taking MER/29. Dropping things, listening without eye contact, fainting under the shower, and body odour may be signs of benzodiazepine addiction.

The current tendency to replace the term 'side effects' with the term 'unwanted effects' may be salutary. Doctors may find it easy to consider 'side effects' as trivial but 'unwanted effects' are a bit more worrisome. The effect of cocaine is to produce local anaesthesia, and also feelings of euphoria, energy, alertness, and power. The effects of

opium, morphine and heroin are to relieve pain, suppress coughing, and control diarrhoea as well as to induce feelings of euphoria, warmth, peace, contentment, strength and energy.<sup>35</sup> Each of the four drugs is also addictive and no one these days would call addiction a 'side effect'. It is the major effect against which the benefits must now be measured.

Addiction may be passed off as a side effect of the benzodiazepines and doctors may still believe that the balance of side effects against central effects still justifies their prescription. I cannot think of a BZD survivor who would support this view. The community is as much obliged to take addiction as seriously if it is labelled 'unwanted' in relation to Rohypnol, Serenace or Mogadon as it would in relation to cocaine, opium, morphine or heroin.

If doctors as a group are habitually slack about adverse reactions, they will be less than optimally rigorous when a drug company tries to boost their egos by inviting them into a shoddy trial. Obviously, doctors must not be included in clinical trials unless they have research qualifications or unless their contributions are closely supervised by a scientist or an auditor. Perhaps more conscientious doctors might participate in trials if they were not paid or bribed by the drug houses but invited by a teaching institution to participate in trials as part of their continuing education. Their reward would then be some form of accreditation and enhanced self-respect. Alternatively, doctors could be accredited for trials by their professional organisation and/or a teaching faculty as they now are selected to be examiners of students.

In 1960, the lack of international communication on drugs permitted companies to isolate the bad news about thalidomide. Several hundred deformed babies were born in Japan during the year after the drug had been withdrawn in Europe. The Swedish manufacturer allowed the drug to be marketed in Argentina for three months after it was withdrawn from Sweden. In Italy, sales continued for ten months, in Canada for three.

The use of more than fifty trade names was the single most important factor in delaying an immediate halt to sales.<sup>36</sup> Benzodiazepines also skulk under a plethora of names.

It would be as difficult to stop crowded shelf marketing in drugs as it would be in detergents. However, labelling laws could be refined to ensure that brand names must be coupled with generic and family names to prevent a repeat of the thalidomide scandal - thus, 'Ativan/lorazepam/benzodiazepine'. The House Inquiry recommends

putting the generic name on labels in the same typeface, font and colour as the brand name but one point larger in size.<sup>37</sup> The impact of this would be greatly enhanced if graduate doctors were educated to continue using the generic names they learned as undergraduates. Using a name that locates a drug in a chemical taxonomy can only aid rational prescribing whereas fanciful names detract: could Miltown have caught the imagination of America if it had been marketed as 'meprobamate'?

The pharmaceutical industry's record of misleading advertising justifies requiring it to get approval of advertising before it is published just as it now gets approval of packaging and inserts. Pre-emptive regulation of advertising, as practised in Canada,<sup>38</sup> may be more effective than trying to correct its impact after the event. 'Advertising' would include public relations handouts for the media. The existing structures could easily be expanded to take on this additional chore.

Regulation of advertising could be taken even further. According to Braithwaite, 'the citizen as both taxpayer and consumer of drugs would benefit from government action to force down promotional expenditure and use a proportion of those savings on continuing pharmacological education for the medical profession.'<sup>39</sup> Independently controlled education, of course.

'Dear Dr.' letters are unlikely to coax doctors into better prescribing. In 1971, the FDA sent a bulletin to all physicians publicising findings relating DES and vaginal cancer in offspring: despite this and other publicity, Eli Lilly's sales reportedly increased by 4 per cent between 1971 and 1972. US doctors wrote an estimated 11,000 prescriptions for DES in pregnancy during 1974 and physicians continued to prescribe DES prenatally for more than a decade after six controlled studies had been published showing it to be worthless in preventing miscarriages.<sup>40</sup> It seems that, once a message is accepted, it is hard to shift. Possibly these letters are not even read.<sup>41</sup>

Blatantly misleading advertising is no longer the main problem. Ten years of agitation over the accuracy of pharmaceutical advertising have succeeded to the point where nine out of ten Australian advertisements are free of blatant errors. The major current problem is the drive to replace (cheaper) old drugs with (expensive) new drugs that are no more effective.

Advertising also promotes the belief that there is a drug solution to every ailment<sup>42</sup> while women's health workers are still concerned about

the prevalence of sexist advertising.<sup>43</sup> Both the pills for ills mentality and sexism need to be combated within medical practice itself.

At present, in Australia and elsewhere, we have the spectacle of the most prestigious and most expensively educated of the professions depending for its information on persons who need have no more qualifications than basic literacy and a driver's license. Detailers are told they have a dual role, to sell and to educate, but they are paid to sell and the advice they get to effect sales is 'If you can't convince them, confuse them'.<sup>44</sup>

Braithwaite initially proposed a simple, stem solution: detailers could be stigmatised and forbidden to approach doctors.<sup>45</sup> It might be more constructive if detailers could be professionalised through training courses run to meet industrial needs but not run by industry-pharmacy colleges are the obvious choice. Training in ethics alone is hardly likely to succeed: most companies already have an overt belief in ethical conduct but only the naive take it seriously.

With a professional qualification, detailers would be better able to know when the drug companies are manipulating evidence. The advantage of a professional certification is that it could be lost for unprofessional conduct like telling lies. The change in detailing must be introduced simultaneously with independent continuing education for doctors to ensure that they at least know enough about pharmacology to adopt a position of intelligent scepticism.

Detailers should no longer be the predominant source of pharmacological information to doctors. Doctors must become their own monitors: their complaints to a company about misrepresentation by detailers will be listened to - especially if they write to world headquarters. Local branches are likely to cover up.<sup>46</sup>

### STIGMA VERSUS SHAMING

In 1984, Braithwaite recommended the stigma of the criminal label and exemplary prosecutions as sanctions against misleading advertising.<sup>47</sup>

Five years later, he retreated from this earlier stem position because, he felt, stigmatising only increases resistance as the perpetrators gang up to support each other. 'A regulatory strategy which rejects adversariness as an opening stance can grapple with the counterproductivity of stigmatization.'48 This winsome argument deserves consideration.

The most persuasive illustration of the non-adversarial approach comes from Japan. After the 1978 clioquinol trial, the Tokyo District Court transmitted a public apology from Ciba to Japanese SMON victims. This curious document revealed the extreme formality, psychological subtlety and (to us) unworldly good sense that characterises much of Japanese culture.<sup>49</sup>

The Japanese sought a public apology as well as compensation for the victims because their approach to justice is not so adversarial as its The individual, western counterpart. existing in interdependency with the community, cannot easily escape its mores and feels ready shame at transgressions. 50 The Japanese are not satisfied simply to punish past conduct but expect the perpetrator to acknowledge shame as a means of ensuring that the offence does not happen again. Retribution includes public acceptance of responsibility for the offence, renunciation of it and affirmation of the standards offended against in a pledge not to reoffend. The offender can then be received back into the community. Ciba's apology includes all these desiderata.

Braithwaite calls such processes 'reintegrative shaming', a very effective deterrent: 'Attachments and commitments (interdependency as we conceptualise it) reduce crime when people make use of them to engage in reintegrative shaming.'<sup>51</sup> He suggests that this should apply to the formulation of rules as well as to their enforcement. Negotiated regulations are often as effective as what would be imposed unilaterally by government but the former interfere less with organisational goals.

'Cooperative regulatory cultures therefore have the best chance of sustaining management , consciences that will punish non-compliance . . .  $^{52}$  The ideal is not to have more controls imposed but to have a 'communitarian culture where everyone is the guardian of everyone else when it comes to complying with the law. . .'  $^{53}$ 

Braithwaite's 1989 solution replaces punishment, stigma, and exclusion with a diffuse educational programme.

In short, the theory of reintegrative shaming implies shifting responsibility for monitoring illegality back into the community along with responsibility for dealing with that illegality by informal processes of social control and conscience building. The role of the government then becomes increasingly one of auditing the effectiveness of these community controls, stepping in when they fail, and selecting the most

egregious cases of crime for formal punishment to fulfil the moral education functions of the criminal law and to underwrite the legitimacy of community controls by showing that the state backs them up with severe deterrence when they are snubbed.<sup>54</sup>

He is asking that we convert the traditional western guilt ethic into a shame ethic. Reorienting our entire psychology of sin, crime, guilt and shame would require cultural engineering on a par with the change from capitalism to communism. Cultures with high failure rates in teaching children to read and doctors to read medical literature cannot hope for spectacular success in replacing guilt with shame.

The pharmaceutical industry may be more amenable to a communitarian solution than some other industries because organisations are more likely to comply with the requests of those on whom they are dependent. Thus, pharmaceutical manufacturers are more likely to comply with health departments than are food manufacturers because the former depend on government for premarketing approvals, for testing protocols, and - more importantly - for pricing in subsidised pharmaceutical benefit schemes.<sup>55</sup>

Remembering that companies do not suffer severely in court - if they ever do go to court, <sup>56</sup> we must look for other sanctions. Richardson-Merrell, Grunenthal, Distillers, G. D. Searle, Biometric Testing, and IBT, all suffered on the stock exchange due to adverse publicity. This is one reason why `. . . corporations fear the sting of adverse publicity more than they fear the law itself.'<sup>57</sup>

Since adverse publicity is the best, cheapest, quickest, and most flexible way of influencing drug companies, Mokhiber proposes that adverse publicity sanctions should become mandatory and the punishment should include disclosure of what measures have been taken to remedy the situations.<sup>58</sup>

Remedial advertisements for misleading promotions can be both an effective means of informing doctors of the truth and an expensive exercise for the corporations - especially if they replicated the original advertisement in size, placing and number of insertions. Since doctors probably do not read 'Dear Doctor' letters, their messages could usefully be published over a full page in daily newspapers.<sup>59</sup>

Offences associated with rogue drugs are fostered by value systems within and beyond the medical-industrial complex. Diana Dutton, examining detailed United States case studies of DES, the artificial heart, the swine flu immunisation programme and genetic engineering,

finds that many factors contributed: an ethos in which corporations take risks but the public takes the consequences, the valorisation (and funding) of high cost, ineffective medical technology over low cost, effective primary care, and the degradation of health to a commodity, available only to those who can afford it. Eventually, corporate crime melds into community ignorance, neglect, and macho risk-taking. But to acknowledge that the medical-industrial complex shares a naive optimism about things scientific and technological with the broader community is not to absolve it.

The mateship system among the medical profession and its apparent pusillanimity before the drug companies makes me doubt that shaming could ever work for the medical sector of the medical-industrial complex. Even a high-level discussion of contentious medical issues may make concessions to the commercial end of the complex.

David Wheatley, editing the Forum on Clinical Pharmacology and Therapeutics (*The Anxiolytic Jungle: Where Next?*) for the Royal Society of Medicine, London, (1990) included a piece that could have been written by a student of Mickey Smith.

In 1973, Dr. Frank Wells published an influential report of a comprehensive changeover of patients in his group practice from barbiturates to nitrazepam/Mogadon, believing that he was moving from a drug of dependence to a clean drug. He missed the possibility of cross dependence and the fact that if he had moved patients from nitrazepam to barbiturates, the results would have been just as good.<sup>60</sup>

Almost twenty years later, representing the Association of the British Pharmaceutical Industry, Dr. Wells published a whitewash entitled 'Industry, Doctors and the Law', which includes a claim that evidence on the potential side effects of nitrazepam was not available when he was weaning barbiturate addicts onto BZDs. <sup>61</sup> Yet we have seen that the evidence was more than sufficient: no fewer than forty-two publications related to addiction had appeared in English alone by 1973. <sup>62</sup>

Articles like 'Industry, Doctors and the Law' make one ask how shaming can possibly be used against doctors who see nothing untoward about unwanted effects and cannot be persuaded to report them? And if doctors are unwilling to offend their accomplices in the medical-industrial complex, how much less ready will they be to scrutinise their own fraternity? Very few doctors are willing to rebuke another doctor.

Almost annually, the muckrake turns up cases of senile, addicted, greedy or simply incompetent doctors whose careers terminate in a coronial inquiry after their professional association has failed to expel them for dangerous conduct. Intervention then comes from the police. This laxity in policing the deviant goes beyond individual negligence. Every state has its Chelmsford: an atrocity as well-known to the profession proportionately as Dachau was known to the citizens of Munich and, like Dachau, taken for granted until external forces rendered pretence impossible.

Abusive doctors are sometimes talked to by colleagues and administrators, who may then invoke other talkers-to up to and including a formal committee. But the purpose is less to rectify professional deviance by shaming than to contain it. According to William J. Goode, the real function of this sort of self-regulation 'consists to a large degree in the protection of the inept within the group and the protection of the group's self-interest from the excesses of the inept'. <sup>63</sup>

Illich describes the same phenomenon in stronger terms: 'The existence of a few charlatans or racketeers has always served the credibility of the medical guild: by denouncing their misbehaviour, the typical practitioner could legitimatize the abuses inherent in his ordinary practice. In the same way, exploitation by individual doctors now blinds people to the exploitation of the commonweal by the health profession as a whole.'64

Braithwaite's argument that shaming is more likely to prevent recidivism than punishment is subtle and persuasive but difficult to put into practise. The process can only work in small populations with homogeneous mores: in Crow Indian tribes, Chinese or Cuban villages, on a ship, or within a firm.<sup>65</sup> It is obviously easier to get firms to adopt shaming than to introduce it to the medical profession.

Management already knows that once hygiene factors - such as wages, hours, and conditions of employment - are taken care of, higher order satisfactions must be met. 'Rah 'rah rewards such as certificates and plaques, speeches and handclapping that recognise achievement and boost self-esteem are effective in excess of their intrinsic value.

Shaming could easily be built into a system that already employs praising as a motivator. Charlie gets a certificate and a publicly administered pat on the back for selling a squillion gross of something safe, Ted is publicly rebuked for selling clear cell carcinoma, limbless babies or addiction.

Firms already have concepts of excellence and quality control that are only now being discussed within the medical profession.<sup>66</sup> Furthermore, many doctors, working as self-employed professionals, are outside any structure that could administer shaming. Medical boards are notoriously hostile to freedom of information and actively reject the idea of public shaming even when cases of medical recidivism show that their private, internal processes do not lead to reformed conduct.

It is also difficult to imagine rituals that would have a suitably shaming effect on doctors. Braithwaite refers to the practice of breast-beating in Republican Rome as an instance of shaming. Such rituals are more inconvenient to the victim than the perpetrator: benzo junkies are too mentally and physically exhausted to inveigh against doctors in a public place.

I am personally too busy and too sick to follow my doctor around in mourning sackcloth with dishevelled hair chanting grievances, though I would be quite prepared to relieve him of all his assets and let his wife and children follow him around chanting. I might even make time to follow them occasionally in his Porsche - just to point up the lesson.

Doctors have a well exercised capacity for denial - another indication that their education has not been properly scientific. The current BZD discussion is carried mainly by survivors supported by social workers with the sympathy and occasional help of a very few compassionate doctors - and the media.

Some doctors in the by no means widespread debate are saying that their colleagues failed to inform patients of the risk of addiction and the correct use of the drugs because they themselves did not know the drugs were addictive until very recently, while others are saying that the information was available, that the doctors told the patients and the patients did not listen. Neither group seems to have noticed what this inconsistency implies for the credibility of the profession.

In the *Couchman* program on BZDs that was filmed at the outbreak of the Gulf War and screened at its close, doctors were confronted with numerous survivors. None of the doctors acknowledged that iatragenic addiction is an appalling experience and one sixteen-year-old girl had her story dismissed as 'very sad' but 'bizarre' and 'atypical'. The inconsistency between what was allegedly known and what was allegedly told was vividly evident.

An organised claque used the occasion to agitate for increased fees: three doctors, who were cut to one for the screened version, rose at studied intervals to repeat a patently rehearsed argument that BZDs were prescribed because the Commonwealth refunded no more for a twenty-minute consultation than a ten-minute one. A patient delivered a commercial on behalf of her holistic psychiatrist, who was sitting behind her; she was also absent from the final cut. Dr. Mathew, President of the Victorian Branch of the AMA, referred to the unsatisfactory fee structure. None of the doctors met the challenge that the problem was not length of consultation but quality of service.

In June 1993, when the Princess of Wales gave her speech on women and psychotropic drugs to a London medical conference, Dr. John Pead, Director of Victoria's Pleasantview drug services centre also blamed the ten-minute consultation for using BZD instead of counselling.<sup>67</sup>

The heightened threat of BZD to the aging brain has been well documented for some time: symptoms of addiction are interpreted as the onset of senility. The older the brain, the more easily and completely it becomes addicted. Thus, some BZDs that are not normally available in the Australian NHS are available for residents of Commonwealth-funded nursing homes who have been on BZDs for at least six months and who have been unable to benefit from a withdrawal attempt. The effect on arthritis, dementia and incontinence is cruel. In spite of this, a doctor on the *Couchman Show*, describing himself as a gerontologist, defended the use of pills to calm an eighty-year-old woman living alone and frightened of burglars.

Many studies show that wilful and erroneous non-compliance among patients ranges from 30 per cent to 80 per cent and that patients remember only about half of what is said to them even when interviewed within minutes of a consultation. <sup>69</sup> The reason for this is at least partly poor communication from doctor to patient and wickedly ineffective information in drug packages.

But there is also a cockeyed attempt at self-determination among patients who try to exercise discretion in matters affecting their own and their children's health. Sometimes non-compliance is an intelligible response to side effects that may lead the patient to adopt a sceptical attitude towards doctors and a conviction that pharmacists are usually more helpful than medicos.

Medical information is not easily communicated.

The medical-industrial complex took one hundred and thirty years to identify and respond to the risks of aspirin. In children, it can cause Reye's syndrome, a potentially fatal liver condition, while adults suffer from stomach bleeding that can progress to ulceration. In 1986, the Federal Government warned against giving aspirin to children under sixteen but a survey published in 1991 found one-third of parents were still giving it to children to reduce fever although 65 per cent of women and 47 per cent of men were aware of the risk. Only 8 per cent of women and 9 per cent of men took their information from the warning on the package.<sup>72</sup>

But patient package inserts (PPIs) may work better than package labels: we know that inserts are read and that even the less well educated can learn from them.<sup>73</sup> The House of Representatives Inquiry came down against PPIs and for pharmacy computer print-outs.<sup>74</sup> This is a curious decision because the problems of communicating complex material to a widely varied audience in the printed word are the same for both media. Perhaps the print-outs shift the cost away from the drug houses?

The rules of communication are exceptionally well known: verbal messages must be clear and simple, backed up by carefully prepared messages in print; allowance must be made for sex, class and ethnic differences in communicating and interpreting information; anxiety must not be allowed to create noise between messages sent and messages received. Drug marketers can design effective packaging if either government or consumer pressure requires.

The evolution of packages for oral contraceptives is less well documented than the evolution of the Coke bottle but it is still a clear example of responsive, responsible and creative packaging. It shows that the drug houses can package responsibly and keep up their profits. All they need to do is bring all their packaging and information up to the level of their best lines.

Reforming commercial practice and weakening the relationship of doctors and detailers and doctors and drug trials would certainly go a long way to reforming the medical-industrial complex. This would be incomplete without specific reforms within the medical wing itself at present, prescribing is not rational and customer relations are abysmal.

### INFORMATION IS THE CURRENCY OF DEMOCRACY

The role of the media in drug scandals is inconsistent: if presented with an outrage, such as Chelmsford, or modest heroes like Phillip Vardy, who publicised Dr. William MacBride's faked experiments, journalists are entirely capable of following stories through but they are equally likely to promote dubious drugs and unproved procedures at their inception. Television journalists defended Melan Bric's spurious cancer cure although a drover's dog would have called him a charlatan. As Mickey Smith's *Small Comfort* proves, the tranquilliser bonanza was helped enormously by complaisant journalists who liked to see lions fed Librium. The media flutter over Christian Bamard's first heart transplants did not include reports that the procedure was so dicey that no further progress was made in for the next ten years.

But they failed to learn in the interval between Barnard and the Jarvik 7 artificial heart. Diana Dutton tactfully describes the media's role in the artificial heart fiasco as 'insufficiently critical'.<sup>75</sup>

The Australian media are insufficiently critical about the success rates of IVF, reproducing interview and press release material but rarely asking the vital question - the only question, so far as the clients are concerned - what proportion of treatments result in a take-home baby? Not a conceptus, not a pregnancy lasting at least twenty weeks, but a gurgling, squirming, growing, healthy baby? The improved results touted by the doctors are real enough if compared with previous abysmal results but if couples want a healthy THB, their chances are much less than an each-way bet.

Doctors, who neglect to use the use available avenues to report even serious adverse drug reactions, <sup>76</sup> misunderstand and resent the role of the press in drug scandals. *The Anxiolytic Jungle* is easily the most detailed, comprehensive, short, recent medical coverage of the BZD issue, yet it contains several slighting references to media intervention that represent their role as 'unhelpful' and imply that it derives from someone's unacceptable desire for publicity.<sup>77</sup> Unhelpful to whom? Publicity for what?

The media are called on to intervene when a rogue drug is out of control and rogue drugs get out of control because members of the medical profession abnegate their responsibility. Publicity may be 'unhelpful' to doctors but to survivors, the media are wonderfully helpful. There are more genuine complaints than spurious. I have often seen decent, average people in BZD support groups speculate

about the possibility of a television investigation with the same wistful intensity that inmates of Belsen must have felt as they listened for American planes.

If, as Braithwaite claims, 'investigative journalists played a more important role than health regulatory authorities in many parts of the world in saving children from thalidomide', <sup>78</sup> then we must make the journalist's job easier by comprehensive and inexpensive freedom of information schemes. Journalists should be encouraged to look beyond public relations handouts to see precisely what foundations exist for the extravagant claims in the glossy brochures.

Since neither mould nor lies flourish in sunlight, we must strengthen the role of the media by creating a space in which community surveillance could assist the final testing of drugs. Since self-regulation and peer review have failed so abysmally, let us try consumer review and government regulation.

### WHOSE LIFE IS IT?

One reason that so few people sue is that doctors are possessive about records, seeing them as simply a memory aid for their own professional convenience and possibly as a marketable commodity-the equivalent of goodwill in a local business. Deregistered doctor, Ian McGoldrick, felt that patient files were sufficiently marketable to justify going to the Supreme Court of Victoria to retain his title in records of patients at clinics managed and operated by him.<sup>79</sup>

In the USA, despite widespread publicity concerning the need for vigilance among both DES mothers, who are at risk of breast cancer, and daughters who are vulnerable to vaginal, cervical and uterine cancers, few doctors bothered to search their records for exposed patients. Some claimed to have lost the charts of treated patients and some even denied that patients had received DES despite proof to the contrary. By 1980, fewer than one tenth of the at-risk DES women had been located and told of their risk. Lack of a clearly defined legal right of access to medical records in Australia disadvantaged claimants in the Dalkon Shield affair and no doubt will also handicap BZD claimants, should a class action occur here.

Thus, a profession that is individualist to the point of anarchy displays a major characteristic of entrenched bureaucracy: jealous control of paperwork at the expense of the clientele that are allegedly

the beneficiaries of their service. Many, no doubt, resent any loss of control over any part of the doctor-consumer transaction. Some have a guilty conscience about their own performance - even though it is not immediately at issue. Most simply do not want to waste time in court.

'It is likely,' forecasts Peter Cashman, a crusading product liability lawyer, 'that the ... barrage of litigation arising out of the Dalkon Shield saga will soon be added to with the initiation of legal proceedings against doctors and hospitals denying access to records.'81

This prediction is close to fulfilment. In May 1992, the Medical Defence Associations of Victoria and NSW both advised doctors not to release records to women suffering from breast implant injuries.<sup>82</sup> Doctors need to be educated to see litigation as a form of quality control that enables them to offer a better service.

Obviously, courts should devise ways to expedite hearings for doctors and make their participation in justice seem more of a responsibility and less of a chore. Medical schools could stop teaching an adversarial approach to law.

### **TERRA AUSTRALIS**

Australians are disadvantaged by inadequate or needlessly complicated laws - particularly by the division of regulatory powers between the Commonwealth and the States. This can lead to anomalies such as the lack of standards for IUDs under the Therapeutic Goods Act of 1966. In 1970, IUDs and other therapeutic substances and devices were brought under the Customs (Prohibited Imports) Regulations 1956, and thus testing was required. The Trade Practices Act has no standards for contraceptive devices although standards exist for imported diaphragms and condoms. 'It seems incongruous,' writes Peter Cashman, 'that devices which are less of a health risk and less intrusive than IUDs should be subjected to greater government controls.' The States and Territories operate separate drug scheduling systems and thus different standards of care - although this situation is slowly being rectified. 84

Australia neglects to budget for testing imported drugs and leaves itself more or less completely at the mercy of multinational firms for information on them. 'Evaluation' frequently means evaluation of literature supplied by the companies themselves. The Dalkon Shield case revealed that, so far as America is concerned, Australia is just

another Asian country.<sup>85</sup> Certainly, local doctors were not reporting complaints, possibly because of their own complicity in fitting the devices without warning patients of unwanted effects. ADEC's (Australian Drug Evaluation Committee) reliance on Robins' literature is unbecoming in a bastion of public health.

Nevertheless, Australia has a commendable reputation for compliance, compared with the United States of America. Most companies prosecuted under the consumer protection provisions of the Trade Practices Act introduced at least some measures to prevent recurrence of the offence.<sup>86</sup> It will be a challenge to see if the Act could be amended to have an influence on the pharmaceutical industry.

Australia could usefully streamline the relationship between state and federal authorities, refine the consumer protection sections of the Trade Practices Act, and adopt a more rigorous approach to both testing and evaluation.

But a more ambitious solution might be to take advantage of the country's insularity to demand higher standards of the manufacturers. It would be relatively easy to build up the CSIRO as a local producer. The Organisation already produces a range of drugs that could be extended to include all those on the World Health Organisation list of essential drugs. A carrot and stick approach could be used to encourage industry both to undertake more local research and to improve standards of promotion among multinationals allowed to market here.<sup>87</sup>

Since almost no new drugs are genuine innovations, Australia would lose nothing by refusing to permit the import of drugs during the P-license period when new drugs are tested on the general public - say, the first year after the launch. A special import license could be available for those patients, for example AIDS victims, who are desperate for treatment and willing to risk insufficiently tried drugs.

From being a banana republic to the pharmaceutical industry, Australia could become an exemplar.

# CHAPTER 7 DON'T PANICREMEMBER PEARL HARBOR

Do not neglect those duties that will keep you from the nut-house!

Katherine Martha Houghton Hepburn

## A PARFIT GENTIL KNIGHT

It was New Year 1989 and five months after I flushed my last Ativan down the toilet, so I took my claggy chest to my suburban GP instead of to the doctor at work.

'I'm not sure if I'm really ill - the pills create so many bizarre feelings . . .'

He is a gentle soul, a Russian Jew who succeeded in getting out of the Soviet Union in the days when Refuseniks were denied visas. His manner, like his desk, has a subtle austerity that reminds me of the consulting rooms of my childhood.

When I first told him of my addiction, he earnestly asked whether I was also addicted to tea, coffee or sugar.

Noting that my temperature was up and that he could hear wet patches in my lungs, he pressed his fingertips in under my floating ribs, feeling for my liver. I winced ever so slightly.

'Go on ... I'd rather you didn't do it but I know you have to!'

But Dr. Gentle's forehead crinkled and he winced in sympathy. 'When did you say you stopped taking the pills?' he asked-and clucked when I told him.

'There is a consultant at the teaching hospital,' he said, 'who uses a lot of benzodiazepines. He might be able to help.'

The consultant had exquisite manners but he kept a room that would have delighted Dickens. Books and medical journals cascaded from every horizontal surface and a complete family of shakuhachi bobbed from a hook behind the door. I was puzzled by a faint smell of

turps until one day I dropped my purse, and peering under a sofa, found a dusty paintbox, palette and brushes among the elf locks.

I hoppity-skipped through my much repeated story until I got to the bit where I said 'So I threw them down the loo!'

'How marvellously brave of you!' he said feelingly.

That won me. I thought that I had met my parfit gentil knight.

'Fred Manners?' said the thoracic bod, 'I went through with him. Brilliant! You have chosen wisely!'

'Fred Shy?' Dr. Manners returned the compliment. 'He's a Christian. He really cares about his patients!'

I had sometimes been impatient in the TRANX group with people who advocated drinking a lot of water and going through Yin Yang purifying routines as if the problem were a poison that could be washed out of the system. Then I made a similar mistake myself. In my brief stay at University Women's College, a girl in my corridor had been working on barbiturate antagonists in Chemistry. I had hoped that Dr. Manners would have some such thing to put an end to my withdrawal symptoms. But antagonists are no help for withdrawal. An antagonist would initiate withdrawal if someone were taking BZD. It would not correct the changes in the brain chemistry of someone who was off the pills and still suffering.<sup>1</sup>

Dr. Manners lectured on BZD to medical students at one of the Gothic universities. He lent me a couple of textbooks and the one hundred and nineteen articles on which he based his lectures. Despite great tiredness and difficulty in concentrating, I felt at home with his mind. Each article was summarised, annotated, and cross referenced much as I would do it myself. The notes were full of chemistry but had nothing on addiction.

I had already been through this disappointment with Muller's Benzodiazepine Receptor - pages of pure science with almost no recognition that living people were using the drugs.<sup>2</sup>

I contained my irritation at the dearth of useful information because Dr. Manners was so exquisitely kind. When I expressed concern, common among BZD survivors, about permanent brain damage, he immediately ordered a scan although it was transparently obvious that

he did not believe it would reveal anything. Nor did it. Scans are not sensitive enough to detect impairment that shows up readily on appropriate psychological tests.<sup>3</sup>

Dr. Manners thanked me for drawing his attention to the problem of tolerance, which explained some of the unexplained fits he had observed in his own patients. He seemed genuinely interested when I suggested that BZD tolerance was comparable to the rebound from L-DOPA that took place so soon after the apparently miraculous cures of Parkinsonian patients. He was not much interested in TRANX except to suggest in a pained voice that the support group really should have medical input. I was slow to understand what this meant.

Over the year that I saw him regularly, and met him socially with some of his colleagues, I realised that Dr. Manners thought I had had an idiosyncratic response. Eventually, and sheepishly, he admitted it.

'I thought you were making it up - about the support group and the withdrawal symptoms and all so on,' he said through his pizza one lunchtime, speaking to the left wing of my glasses, 'I thought "If I don't know there's a problem, and my junior doesn't know there's a problem, then there is no problem." Then I met Professor Guppy in the corridor and said "Fred, is there a problem?" And he nodded.'

Dr. Manners was on the editorial board of a pharmaceutical journal that did not depend on drug-house advertising. When he asked me to recommend someone to review the BZD problem, I proposed a woman doctor, experienced in substance abuse, active in her profession, and already published on benzodiazepine addiction. As my mentor scanned her CV and the sample article I gave him, I skimmed a copy of this publication. I saw that my nominee had a qualification that I had not noticed - she was also on the editorial board of the journal.

## **GETTING THE FACTS**

How many generations of students had marvelled at Dr. Manners's brilliance, kindness and courtesy yet been permitted to become drug pushers by his indifference? I had already lost my faith in academic doctors and was seeking help from a different network.

Rhonda Galbally, who was then running Victoria's Quit Campaign, introduced me to Dr. Illona Kickbusch of World Health Organisation, then visiting Australia for the Healthy Cities Programme. I was grateful

for the femocrat connection. Dr. Kickbusch was well aware of the BZD problem, for she had worked with Dr. Graham Dukes, who was with WHO and is also Professor of Drug Policy Science at the University of Groningen.

Professor Dukes, qualified both as a medical doctor and as a lawyer, is the author, with Barbara Swarz, of the elegantly written Responsibility for Drug-Induced Injury.<sup>5</sup> But when Dukes and Swarz were writing, Halcion/triazolam was the main BZD to have been investigated in the courts and there were still no definitive cases. Although his book was not much help, Professor Dukes did send me a useful bibliography.

At the same time, I was looking for information on the Christine Holt case. The *Coming Out Show* episode on BZD had reported that a Perth housewife had been awarded twenty thousand dollars when she sued her psychiatrist for getting her addicted to Lexotan/bromazepam. But news goes out of date quickly and *Coming Out* had no details. My first lawyer charged me three hundred dollars for organising a search and his associates, after looking in only one of the three possible archives for the case, sent me a bill for one hundred and thirty dollars and a request for more and better particulars.

I checked the time lag between Melbourne and Perth before ringing Beth, who is one of the most self contained and self-directed women I know. She teaches German and learns Russian; she paints and exhibits; she writes poetry and illustrates the books she publishes herself; she nurtures her house and garden, watches birds and rides pillion on her boyfriend's motorbike. In her early thirties, she decided against children and had her tubes tied. When second wave feminism hit Australia, she was at a polite loss to know what the problem was. In less than twenty four hours she rang back.

'Dr Hoffman is the man you want!'

She followed this up with a couple of pages of notes. And all for friendship!

Like Professor Dukes, Dr. David Hoffman is another lawyer-doctor and a Maccabee as well. Someone had forgotten to write a shut-up clause in the Holt-Finnemore settlement so he was free to send me a copy of the case as well as the research behind it.<sup>6</sup>

Believing my addiction symptoms to be sickness and not neurosis, I had done the rounds of doctors without getting the slightest enlightenment. In 2.5mg addiction, I had explored pelvic pain, a stink in my sweat and breath, bloated stomach, a misery in my upper left jaw, blurred vision, clumsiness, dropping things and falling over. In 1.25mg withdrawal, I had sought help for excessive drinking and hallucinations but not for tinnitus because I had seen it as a nuisance more than a problem. I learned to despise the medical profession.

A determined patient could inundate a doctor with symptoms that had no apparent meaning - like the scads of information that overwhelmed the United States intelligence before Pearl Harbor. As I read these photocopies of photocopies, making yet more copies for lawyers, journalists and sufferers, I felt like someone who has been poring over a thousand-piece jigsaw and at last begins to see recognisable patches here and there.

Dr. Heather Ashton reports on a group of long-term users at therapeutic dosage: the vast majority had panic attacks; 20 per cent had had overdose requiring hospital admission; 20 per cent suffered from incapacitating agoraphobia; 18 per cent had GI investigations for irritable bowel; 10 per cent had undergone neurological investigations.<sup>7</sup>

Given the inefficiency of postgraduate medical education, a woman who persists in complaining of cystitis in the absence of a positive culture or supporting symptoms is likely to be labelled neurotic and ridiculed but a painstaking doctor might elicit that her real problem is too-frequent micturition deriving from excessive drinking (polyuria/polydipsia) - a standard withdrawal symptom.

Once patients know they are addicted and/or withdrawing, they do not know when it is appropriate to seek help. Martin, a cheery fellow who often made constructive suggestions for other survivors at the support group and whose only negative contribution was a guttural growl whenever he heard the world 'Ativan', asked whether he should go to the dentist for an apparent toothache.

It seems a silly question in a quite sensible middle-aged man but it was intelligible in the circumstances. We agreed that if he went to the dentist and had no real problem, no harm would follow but if he had a real problem and did not go to the dentist, he might lose a tooth - so he went to the dentist.

I had had a misery that moved around my head when I lay down, producing a sense that every screw on every plate in my skull was being systematically tightened and intensifying to form a painful band starting behind left ear and ending in front of right ear. I was embarrassed at the difficulty of explaining to my intelligent, sensitive, droll, irreverent dentist that I wasn't sure what the trouble was.

Since I had in fact had a less than perfect root canal filling done in London, it was possible to interpret the misery as discomfort from this botched job. That molar has now been drilled into three times.

Some symptoms are so obviously physical that they can startle. On one regular checkup at the mega-hospital, a resident prodded under my ribs and leaped away when he found the same gross, painful distension that had worried Dr. Gentle. Facing into the passageway at the back of the cubicle, he cried 'See your GP! See your GP!'

I was moderately interested in his lack of self-control, his concern with the symptom, and his lack of concern about my feelings, but I had already seen my GP who had found nothing to hang a label on. I later discovered that abdominal bloating and tenderness is a common symptom both of addiction and withdrawal.

## **DIAGNOSTIC NIHILISM**

Benzodiazepine literature is generally remarkable for the absence of the patient. This can be explained on good orthodox grounds: doctors invoke science to minimise the value of personal accounts of difficulties in stopping BZDs – 'which may be very persuasive but do not constitute scientific evidence'. This depends on who defines which scientific procedure is to be used - there are more than one.

Doctors, regrettably, lack the range of communication skills essential to their job and are slow even in recognising their handicap. Reluctance to listen among some patients and inability to explain among some doctors is exacerbated by myths held by the latter about the frowardness of the former. Doctors frequently argue that informing patients about unwanted effects of a drug will cause them to mimic adverse reactions by suggestion, even though there is evidence that not preparing patients for likely side effects or leaving them confused about the instructions may lead to non-compliance.<sup>9</sup>

We do not know whether the policy of concealing possible adverse reactions does control phonies but it certainly sacrifices genuine sufferers and prolongs their quest for diagnosis of unwanted effects.

In any case, doctors do not have the legal right to withhold information on the basis of their prejudice: the patient has an obligation to be vigilant in his or her own welfare and the doctor has an obligation to inform the patient.  $^{10}$ 

Doctors can easily distinguish innocently imagined side effects or possible malingering from genuine pharmacologic reactions either by taking the patient off the pills, noting the changes, restoring the pills, and noting the changes or by asking the patient a structured series of if/then questions. This simple algorithm is then scored to establish standardised assessment of causality (SAC).<sup>11</sup> I've never met a doctor who used SACS.

The standard objection to SACS, apart from the unacknowledged resistance to the investment of time, is that they do not measure the unmeasurable, subtle, humanistic factors. That is, doctors reject subjective, humanistic, patient testimony as unscientific but, given the chance, refuse to put their own dealings on a measurable scientific footing. The medical profession is immune to even constructive criticism of their practice.

It would also be extremely simple to apply a test-retest format to personal testimony. Patients could be interviewed twice in succession by different interviewers or, after a period of months, by the same interviewer and the results compared for consistency. Or the problem could be subjected to action research - the progressive modification of hypotheses as new information is found. Addiction and withdrawal are also ideal subjects for phenomenological interpretation - the search, not for absolute reality, but for constructed reality, the reality we live. Even a simple ethnographic study of patient histories and experiences would provide useful, perhaps salutary, information.

These and other research methods are unacceptable to orthodox medicine ostensibly because they are not properly scientific but covertly because they belong to a different tradition. They shift the focus from the disease or condition to the patient, making it harder for doctors to exculpate themselves from complicity in his or her suffering. Survivors can be useful witnesses but our testimony is embarrassing.

Any doctor who argues that some research models are more scientific than others and that the model most closely derived from physics is most scientific, is showing that his epistemology is more than a generation behind current thinking and exposing himself to suspicion of self interest.

At first, marketers minimised unwanted effects. Loss of memory was treated as incidental to muscle relaxation when BZD was used by injection or intravenously in surgery. Now it has become a unique sales proposition as some intravenous preparations are being marketed as a means of ablating unpleasant memories of surgery.

It was many years before prescribing doctors admitted that normal doses taken both short and long term cause memory loss. A variety of learning and retrieval impairments, not readily apparent, can be identified by appropriate psychological tests. 13

Psychomotor effects are not severe in short-term, low dosage but dementia, amnesia, and falling over were reported in chronic use. <sup>14</sup> Single therapeutic doses of several BZDs affected driving on simulated courses and also affected driving performance in real life situations. The estimated BZD presence in motor accidents ranges from near zero to 20 per cent although the causal relationship has not been established yet. <sup>15</sup>

The police are concerned enough about the influence of tranquillisers on road accidents to request a method of testing for pharmaceutical drugs as they do for alcohol yet the confusion about the nature of the relationship between these drugs and accidents is frequently offered as proof that there is no relationship.

The conservative baseline in literature about unwanted effects is this: addiction occurs in susceptible personalities; withdrawal is more severe on high dose than low; dependence can occur at therapeutic dosage over long periods of time; withdrawal symptoms appear more rapidly and possibly more severely wiith short-acting BZDs; concomitant or prior use of alcohol or barbiturates predisposes to BZD addictions. Withdrawal takes a fortnight.

The liberal baseline is that addiction is unpredictable, unwanted effects are legion, and anyone can be addicted. Addiction occurs anywhere from two weeks to eight months after commencement. Withdrawal takes years.

The elderly suffer increased nocturnal urinary incontinence and 70 per cent greater risk of hip fracture that will soon prove fatal for about one fifth of victims. The Royal District Nursing Service (Victoria) found that 61 per cent of medicines taken by patients in their continence management programme were exacerbating incontinence and that 44 per cent of patients required the nurses to intervene with the GPs. <sup>17</sup>

Memory loss, the symptom most commonly reported to TRANX, is devastating for the elderly because it may lead to them being treated as confused, senile and so on and prescribed other medications such as neuroleptics. Sleeping pills and tranquillisers account for 46 per cent of drug-induced dementia.<sup>18</sup>

The muscle-relaxant effects aggravate arthritis because the sufferer becomes too weak and tired to exercise. BZD magnifies pain and perhaps even causes it, which is a deterrent to self-help. A vicious circle is set up.

When my muscles turned to molluscs I had more pain than I have ever had before. Twisting at the waist on a library ladder - which I was bound to do quite often because books are my tools of trade-I sometimes found myself transfixed in agony. If, trotting to the morning train, I forgot to pay attention to my posture, I might double over with pain that could only be relieved by forcing myself upright, lifting my hip and resettling it on my thigh-bone. God be4D the little old ladies in nursing homes!

With the exception of epileptiform fits, doctors tend to treat symptoms as trivial but symptoms also have social consequences that multiply the distress. The unwanted effects of BZDs are not trivial. They include both costs to the taxpayer and harms to the users.

Memory loss can be tragic for the aged but it has a more insidious effect on the lives of younger age groups. The commonest complaint among women is loss of life experiences within the family - addicts do not see their children growing up.

I habitually write brief reviews of any good or interesting film as a source of social history but my diaries for the years 1985-87 contain cameos of films that I cannot remember seeing. When I view them again, I do not have the pleasure of recognition - only an uneasy sort of deja vu. Books from that time are annotated in detail in my usual reviewer's scrawl but, if I were questioned on oath, I could not claim to have read them.

I discovered that my hostess bad been complaining about my stink from the fact that her daughter said 'Don't worry, I'll sit next to you!' when her mother moved to the other end of the table.

I greatly admire Thomas Szasz and my normal self would have been delighted to meet the author of The Myth of Mental Illness and The Manufacture of Madness, to learn from him and argue with him but when Frank invited me to dinner with Szasz, I was inert and lacklustre, fading in and out of sleep at the dinner-table.

Gagaku is the only dependency I acknowledge - stately and soothing yet stimulating. The Showa Emperor was still alive when Fumiko took me to hear his Gagaku consort, which almost never performs in public. Dozing stupidly and rudely, I spoiled a pleasure that can never be repeated.

During the interval between when Caroline asked me to be her birth attendant and when Georges called to tell me that labour had started, I was increasingly depressed, tired and stiff! I did get there for the birth but I was about as useful to my friends as Banquo's ghost.

I regret these small erosions of love as much as the greater harms.

Despite the plethora of evidence on BZD harms, survivors have enormous difficulty getting help because the medical profession chooses not to come to terms with problem. It adopts all the standard defences: addiction does not occur; it does occur but on an infinitely small scale; it does occur quite commonly but it is nothing to do with us; it does occur quite commonly but all you have to do is prescribe more pills; the victims do suffer but they asked for it; etc., etc., ad infinitum, ad nauseam.

When TRANX ran a splendid national conference on benzodiazepine use in 1991, with financial support from the Federal Pharmaceutical Benefits Education Programme, fewer than one hundred persons attended; only about sixteen of them were doctors. A similar conference in Adelaide had also failed to attract doctors. <sup>19</sup>

# Doctors get people addicted and paramedics have to get them off their pills.

Doctors frequently claim that a withdrawal syndrome does not occur because what the patient has is re-emergence of his or her original symptoms. They do not bother to compare putative withdrawal symptoms with those the patients originally had. Many patients did not have anxiety or insomnia - let alone the more florid withdrawal symptoms. I initially had a cyclic mood swing every second morning that made me feel like death warmed over and reluctant to get out of bed.

During addiction and withdrawal, I developed these symptoms:

- anxiety
- the BZD face
- distortions of taste and smell
- cognitive effects
- disturbed concentration
- disturbed sex and emotions
- spectatoring
- hesitancy in making decisions
- loss of social skills
- depersonalisation
- Transcendental Meditation ineffective
- grossly abnormal stress responses
- general pain
- pre-existing illnesses all much worse bronchiectasis, asthma
  - arthritis
  - allergies
- loss of muscle tone
- pelvic pain
- stink
- gastritis
- oedema
- neurological symptoms
- compulsive chewing
- failing
- tiredness & insomnia
- transient ischaemic attack
- pressure in head.

This is a naive list. I compiled it for the House of Representatives Inquiry into the Prescription and Supply of Drugs, working from my diaries *after* looking at Dr. Manners's pure science material, which did not deal with addiction, and *before I* had received more relevant material from Dr. Hoffman and Professor Dukes. $^{20}$ 

Doctors also use a more subtle version of the re-emergence defence: withdrawal symptoms are a minor image of the symptoms for which the drugs are prescribed and therefore difficult if not impossible to distinguish. This claim, like the previous one, assumes that the pills are prescribed according to their proper indications - an assumption that is often incorrect.

Some patients are in a tight situation but not suffering from anxiety. A woman who went to her doctor for flu found that he had added Serepax/oxazepam to her prescription without asking her. She queried this

'You're staying at the Women's Refuge. All the women at the Refuge are on Serepax!' he said.

'I'm the social worker!' she replied.

When she told me this story, she was wearing a T-shirt carrying the refuge logo and the motto 'I hate Serepax!'

Many BZD prescriptions are written to put the doctor out of the patient's misery: bereavement attracts BZD, so does the wife of a violent husband, and the mother of a colicky baby. Many patients did not have anxiety until after they took the pills. The horror of my bad days became a permanent condition after a month or so on Ativan which, incidentally, was prescribed in 1982, the year that TRANX was established and Dr. Heather Ashton helped set up a specialist clinic to support and detoxify BZD addicts in the UK.

One major American review, published in 1987 and still quoted by expert medical witnesses giving opinions for legal purposes, concludes that although prescribing habits are difficult to assess, most prescribing is probably appropriate. A national survey of a representative sample of US physicians in 1985-86 found that 54 per cent of BZDs were prescribed for mental conditions including neurosis, depression, and anxiety, and the remainder for insomnia, circulatory, and muscular-skeletal problems, ill-defined symptoms and senility.

The review concluded 'These data indicate that medical use of benzodiazepine anxiolytics and hypnotics is generally consistent with what is known about the clinical utility of these drugs. These data also suggest that the patient who receives an anxiolytic prescription is typically an older person, probably female, who is afflicted by multiple somatic health problems.'<sup>21</sup> The reviewers were favourably impressed because most prescriptions were given to patients who had been seen previously - and thus was not given on the first visit. They did not query the utility of prescribing for 'ill-defined symptoms'.

While the review acknowledged that the use of BZD was chronic or recurrent in a substantial majority of US cases, they were unable to comment on the fact that most prescriptions were repeats.<sup>21</sup> In 1987, one might reasonably have speculated on the possibility that repeat prescriptions could perhaps represent an addiction problem. Short-term

use had been recommended in the UK since 1982 and British authorities did admit that continued use is mainly due to addictions.<sup>23</sup>

The review also acknowledged that a 'relatively high percentage' of BZDs were given as antidepressants even though this was already contraindicated because of the suicide risk.<sup>24</sup> This did not modify their conclusion about probable appropriateness of most prescriptions.

In 1988, the Royal College of Psychiatrists (UK) summarised precautions for BZD prescribing:

- 1. Benzodiazepines should not be I used alone to treat depression or anxiety associated with depression. Suicide may be precipitated in such patients. [and]
- 5. Disinhibiting effects may be manifested in various ways. Suicide may be precipitated in patients who are depressed ... <sup>25</sup>

TWO years later, Pippa was prescribed Rohypnol.

'I had just broken off a love affair,' she said chirpily,"and I wasn't sleeping so well so the doctor gave me Rohypnol. He said it was quite safe - non-addictive and so on. Things got worse and worse. I was unreal. The world was unreal

And, you know, they're very easy to take - I mean to ingest. One day I swallowed the lot. Having been that close ... you know, it's strengthening. But I do wonder ... if I've got any permanent damage.'

Reading the benzodiazepine literature, I am constantly struck by beautiful trust that many doctors have in their colleagues. 'It also needs to be borne in mind,' writes Peter Tyrer, 'that anxiolytic BZDs are prescribed for acute anxieties which have occurred in response to stress ... The assumption is that ... the distress will be short-term and therefore the BDZ [sic] will be quite safe to prescribe . . .'<sup>26</sup>

Benzodiazepines are not simply anxiolytics: similar or identical drugs are marketed for anxiolytic use but that is by no means a guarantee that they will be prescribed that way. A 1961 New York study found that only 18 per cent of all psychotropic drugs and one third of minor tranquillisers were prescribed for mental indications.<sup>27</sup>

In 1978 Tyrer himself found that half the drug prescriptions by British GPs for psychiatric patients were incorrect.<sup>28</sup>

A 1983 UK study found that only 11 per cent of patients with major depression were using antidepressant drugs but 29 per cent were using anxiolytics/hypnotics and 69 per cent took no psychotropics at all.<sup>29</sup> An Australian survey of 397 aged people in aged care accommodation found that 50 per cent were prescribed BZD and 30 per cent were taking them inappropriately.<sup>30</sup>

Patients are given benzodiazepines for sore throats, skin rushes, glandular fever, flu, ovarian cysts, heart attacks, obesity, asthma, trauma, puberty, stiff neck, mastectomy, palpitations, menorrhagia, post partum depression, back injury, before and after surgery, and for being donged on the noggin with the hatchback of a car.

Barbara Gordon, a highly successful American television film producer, began her tragic encounter with BZD when several orthopaedic surgeons successively prescribed 2mg and later 4mg Valium daily for the bad back that she collected in a bicycle accident. Using the drug intermittently over a twelve-year period prepared her to accept it when a psychiatrist prescribed it regularly for anxiety. Ms. Gordon does not bring the same critical intelligence to bear on her experience that she applies in her work - her autobiography is unclear about whether this anxiety was derived from Valium. We may reasonably assume that it was.

'It was like returning to an old friend,' she writes in I'm Dancing As Fast As I Can. 'I made the mistake of thinking of it as a medicine, not as a drug which should be handled with care.'<sup>31</sup>

While psychiatric groups may be undermedicated and/or incorrectly incorrectly medicated, other groups are medicated overmedicated. Doctors are not simply prescribing the right BZD for particular conditions. 'The act of prescribing is not just determined by the presenting symptoms but is strongly influenced by the social exchanges which take place between doctor and patient during the consultation.' Hence one UK survey found prescribing rates among GPs varied from 15 per cent of patients getting scrips to 90 per cent. Vast differences in BZD prescribing rates were found even within one English provincial city. That is, BZD consumption is doctor-driven not indication-driven.<sup>32</sup> Although the benzodiazepine family of drugs have qualitatively similar effects, they have widely different potencies. Ideally, length of action should determine whether they will be used to induce sleep or tranquillity, 33 nevertheless, 'the usual division of benzodiazepines into rigid treatment categories of anti-anxiety agents and hypnotics did not appear to be based on the known pharmacological or clinical properties of this group of compounds.'34

# The indications for benzodiazepines are determined more by marketing policy than characteristics of the individual drug.

Research reveals many factors, other than accepted indications, that determine if, what and how doctors prescribe. This is a conservative list.

- 1. The quality of the doctor-patient interaction.
- 2. The quality of the doctor's medical education.
- 3. Consumerism and public education.
- 4. Marketing including both the nature and intensity of advertising and promotion. Trawls of advertising in 1970 revealed these indications: heart disease, indigestion, spastic gut, no demonstrable pathology [sic], being a housewife, geriatric anxiety, insomnia, overwork, and depressions. By 1990, the uses were: epilepsy, hypnotic, muscle relaxant, induce amnesia during surgery, alcohol withdrawal, mania, trigeminal neuralgia, anxiety, and jet lag. 36
- 5. Utilisation rates increase when drugs are subsidised.
- 6. Doctors' response to being inappropriately asked to act as social workers (putting the doctor out of the patient's misery).
- 7. Doctors use prescription to close interview and affirm professional competence.
- 8. Fewer psychotropics are prescribed in larger towns than smaller ones.
- 9. The longer the doctor's day, the more prescriptions are written.
- 10. Doctors' job satisfaction less satisfaction leads to more prescriptions.
- 11. Doctors' values and philosophy: 'the treatment of patients with repeat prescriptions for Librium and Valium reflects the doctor's attitudes more than the patient's condition ... it becomes possible that the patient has negligible influence.'<sup>37</sup> Doctors who cannot communicate, have no alternative to offer, want to please, and cannot tolerate anxiety themselves prescribe more BZDs.
- 12. Repeat prescriptions are known to be the habitual outcome of a particular doctor-patient relationship. This may be especially relevant where the patient is elderly.
- 13. Patient demand for drugs.<sup>38</sup>

Doctors who prescribe BZDs are not just matching pills to ills. 'At the moment, prescribing occurs in something like 60 per cent of every GPs consultation,' observes Professor Neil Carson, Department of Community Medicine, Monash University. 'It probably should be less than 40 per cent.'<sup>39</sup> So long as overprescribing and inappropriate prescribing persists, there can never be a presumption that any pill is properly prescribed.

This research also makes nonsense of the argument that, since BZD use is widespread but only a proportion of users become addicted idiosyncratically, 'there are presumably factors in the personality makeup of these patients that encourage them to seek drugs rather than to avoid them and that influences their perception and tolerance of withdrawal symptoms.'<sup>40</sup>

The patient is damned as non-compliant if she refuses any drug prescription and damned as passive-dependent-neurotic if s/he accepts. The reality is that most doctors promote drugs and few patients seek them.

The case of BZD is not the first instance of the medical profession prescribing a treatment substantially for the convenience of doctors and, when untoward effects occurred, blaming the victims for demanding it. In the early decades of this century, elaborations of surgical technique in obstetrics led to increases in maternal mortality. In particular, although obstetric forceps were needed in only a minority of births, they were used in about fifty per cent of deliveries, leading to infection, bladder damage, tears to the cervix and pelvic floor, displacement of the uterus and damage to the baby.

In both Europe and Australia, there were calls for a retreat from accouchement force. The defenders of the practice did not deny its hazards but they appealed to market forces.

According to Dr. E. S. Morris, NSW Director of Maternal and Infant Welfare (1927):

A disinclination on the part of the medical man to expedite delivery is apt to be misinterpreted as inefficient midwifery by the patient and her friends. A practitioner is liable to advance his reputation by the almost universal use of forceps ... So long as one competitor adopts this practice, all other [sic] must show an equal competence.<sup>41</sup>

Since women's response was overwhelmingly horror at the idea of a forceps delivery and regret at the ill-health that ensued, we must infer that the medical men were using forceps to alleviate their own boredom with the tedium of normal labour and to establish a unique selling proposition in competition with their peers.<sup>42</sup>

Possibly patients who stay with doctors for withdrawal really are a special group. It would be interesting to see whether there is a difference between survivors who attend TRANX for withdrawal, those who attend doctors, and those who attend both. Many TRANX users require support for dealing with their doctors as well as dealing with their pills and many attend doctors only to obtain the prescriptions that TRANX facilitators cannot provide. Yet TRANX provides only minimal support, encouraging its clients to develop a withdrawal schedule and to help each other and themselves.

#### WHAT ARE THE SYMPTOMS?

Published lists of withdrawal symptoms vary from six items $^{43}$  through twenty-one $^{44}$  to forty-eight. $^{45}$  This considerable discrepancy suggests that some doctors are not paying attention or some are being too generous.

The following list is compiled from five published sources together with my own observations from the TRANX group and my personal experience.<sup>46</sup> (I want to thank Jan Webb, a nurse-educator, for helping me get them into logical order.)

#### **CENTRAL NERVOUS SYSTEM**

#### **Emotional Symptoms**

- anxiety
- panic attacks
- apprehension
- paranoia
- obsessions, compulsions
- aggression
- depression
- passivity
- sad face
- averted gaze and apparent inattention during conversation
- depersonalisation/derealisation
- agoraphobia/claustrophobia
- suicidal ideation

#### **Cognitive Symptoms**

- poor memory, poor concentration
- inability to read traffic lights, discriminate between coins
- inability to do mental arithmetic

 many effects not available to observation but apparent on psychological testing<sup>47</sup>

#### Perception

- visual and auditory hallucinations
- confusion, delirium
- hyperacuisis: bizarre and painful oversensitivity to stimuli: light, sound, smell, touch, temperature, taste,
- persistent revolting taste in mouth
- sensations on skin: chewing, worms, insects etc.
- sensation of ground moving, walls falling in
- numbness and tingling, electric shocks
- feelings of excessive cold/heat
- pressure in/on head

#### **Psychomotor**

- unsteady gait
- twitches and jerks
- muscular weakness
- muscular spasm, rigidity
- tremor
- loss of co-ordination, proprioception
- falling over

#### **Other CNS Symptoms**

- exhaustion
- sleeping too little or too much
- tinnitus
- epileptiform fits
- headaches
- generalised pain
- localised pain
- reversible dementia in elderly
- sweating
- restlessness
- excitability
- hyperactivity

#### **EYES**

- blurred vision
- double vision
- nystagmus
- acid tears

#### **CARDIOVASCULAR**

- palpitations
- burst blood vessels in the eye

#### **RESPIRATORY**

- hiccoughs
- asthma-like shortness of breath
- slow or fast shallow breathing patterns
- increased bronchial secretions

#### **GASTROINTESTINAL AND HEPATIC**

- dry mouth
- excessive salivation
- excessive drinking
- anorexia
- weight gain/loss
- difficulty swallowing
- nausea
- gastric upsets
- irritable bowel
- constipation
- diarrhoea

#### **GENITOURINARY**

- incontinence
- urinary retention
- menstrual irregularities
- failure to ovulate
- gynaecomastia
- loss of libido
- excessive libido

#### **DERMATOLOGICAL**

- skin rashes
- pruritis
- photosensitivity

#### **HAEMATOLOGICAL**

spontaneous bruising

The crucial question is not whether any or even most of these symptoms are also symptoms of pre-existing conditions or even mirror images of pre-existing conditions but **whether the patients who now complain of these symptoms had them before.** If what I suffered

during addiction and withdrawal is anxiety, then I've never been anxious in my life before. In the support group, one frequently heard 'it wasn't like anything I've ever had before!' The unfamiliar, bizarre, and often indescribable nature of the symptoms is itself a cause of anxiety.

Estimates of how many users get withdrawal vary from possibly 30-40 per cent in general practice to 100 per cent in specialist clinics. That there should still be controversy over whether the symptoms represent withdrawal, suggestion due to media hype, or return of original symptoms seems to be diagnostic nihilism-a way of avoiding the fact that the medical profession has made another mistake and the medical-industrial complex has just committed another offence against the commonweal.

#### WHO GETS BZD?

The prescribing ratio of two females for one male in psychotropic drugs has appeared internationally over many studies for many years. The proportion of females increases greatly in the cohorts after age forty-five and their prescriptions are repeated for longer than three months but this is probably an artefact of cultural beliefs about menopause. The pattern seems to be that more women than men receive them for psychotropic use but more men than women are prescribed them for somatic use.

Doctors seem to have different stereotypes of men and of women, derived from or reinforced by drug house advertising. They probably prescribe accordingly.

However, several factors indicate that the 2:1 ratio in BZD prescription is not simply male doctors sedating female patients.

Women have more consultations than men in roughly the proportion of 60-70 per cent females to 30-40 per cent males. Women are more likely than men to complain of symptoms - especially psychological ones. Since women use more self-selected medications such as vitamins and painkillers, women may be more nurturant of themselves, more conservationist, and respect their own bodies and health more. Women actually do have about twice as much psychiatric distress as men<sup>53</sup> - in response to societal pressures including reproductive stress, poverty, physical and sexual abuse, and unhappy marriage. One survey found that women doctors were more ready to prescribe minor tranquillisers for women patients than for men.

Many prescriptions are for conditions that only or mainly women suffer, for example, disorders of menstruation or pregnancy, and obesity. The prevalence of use for the elderly takes in more women because females live longer than men. For Possibly women have social permission to seek medical help and men to use alcohol for self medication but this argument does not take into account the different processing capacities of the male and the female liver or the depressant effect of alcohol on testosterone. Men may use alcohol to self-medicate for masculinity.

#### WHO BECOMES ADDICTED?

Studies show that the number of addicts in various samples ranges from almost no-one to almost everyone.<sup>57</sup> Dose and duration of use influence whether or not users become addicted: few are addicted in under six weeks of use; the proportion addicted increases between three and eight months and increases considerably after eight months.

Possibly as many as 55 per cent of users have no difficulty in stopping.<sup>58</sup> Some researchers suggest that passive dependent personalities have withdrawal problems and obsessionals do not while past alcoholism or concurrent use of alcohol increases both the risk of addiction and the difficulty of withdrawal.<sup>59</sup> Yet Dr. Heather Ashton and others say that anyone who requests withdrawal can probably be withdrawn and personality disorder or psychiatric history is no barrier.<sup>60</sup>

Presumed characteristics of addicts should not draw attention away from proven characteristics of the drugs.

Short-acting formulae tend to create earlier and more severe withdrawal problems. Some, for example, lorazepam, are cited more often in reports of dependence than their prescribing figures warrant.

#### **HOW LONG DO THE PILLS WORK?**

Tolerance is, of course, an unwanted effect, occurring in animals, humans and the unborn. It develops differentially to different actions such as psychomotor functions, sleep, and the convulsive threshold.<sup>61</sup> Muscle relaxant and anticonvulsant effects wear off after a few weeks. The hypnotic effect is lost in three to fourteen days of continuous use for insomnia and there is no anxiolytic effect after four months.<sup>62</sup> A

study comparing the effects of diazepam, dothiepin, placebo, self help group, cognitive and behaviour therapy, on 200 anxious patients found that diazepam is the least effective and had no action after four weeks. 63 Very few studies control for placebo effect, but those that do tend to find that BZD has little effect. 64

This being so, one must ask how some apologists can persist in justifying long-term BZD use for patients who allegedly cannot function without them when the evidence seems to suggest that they cannot function with them.<sup>65</sup>

Perhaps the question should be 'do the pills work at all?' One survey of the elderly found qualitatively worse sleep using BZD.<sup>66</sup> A correspondent of *The Lancet* claims that BZDs are 'one of the commonest *causes* of insomnia'.<sup>67</sup> Many studies report that simple counselling is as effective as anxiolytic BZDs.<sup>68</sup> The history of benzodiazepines seems to have reached the same point that meprobamate reached twenty years ago: the drugs are addictive and even the best evidence does not sustain claims for efficacy.<sup>69</sup>

## IS THERE A DIFFERENCE BETWEEN TOLERANCE AND ADDICTION?

While some observers emphasise the seriousness of BZD addiction by comparison with heroin, 70 others trivialise it by comparison with nicotine.

Murray and Tyrer claim that both BZD and tobacco induce early tolerance, little or no escalation of dose occurs, and there is a relative absence of search behavior, and withdrawal syndrome.<sup>71</sup> 'It is perhaps no coincidence that the difficulties subjects have when stopping nicotine are approximately of the same order as those stopping benzodiazepines after prolonged usage.'<sup>72</sup>

Now, there is search behavior with BZD, but the pushers are always handy and most of the drugs are subsidized by the tax dollar, which both encourages their use and acts as a governor on increased doses. And nicotine withdrawal does not, to my knowledge, induce epileptiform fits, hallucinations, domestic violence, child abuse, suicide or, indeed, most of the other fifty or so BZD symptoms.

Most patients do not increase the dose: it is more usual for them to get a pill cocktail from their duly qualified medical practitioners.<sup>73</sup> In Dr.

Ashton's sample of patients who had been on low dose BZD for a mean of ten years, 28 per cent were on a combination of BZDs and 62 per cent were given additional psychotropic drugs after starting on benzos. The drugs are used illicitly to potentate street drugs but not for recreation in their own right. Patients with careless or unscrupulous doctors do get up to excessive doses. Ethel Kennedy and Elizabeth Taylor, who were taking upwards of fifty and sixty pills under medical supervision, are not unusual.

Barbara Gordon, who began with 2mg Valium daily, had been taking thirty 5mg daily for years when she came off cold turkey. The increases as well as the brutal withdrawal had been prescribed by the psychiatrist whom she saw weekly for ten years. Christine Holt was prescribed Lexotan/bromazepam 3mg three times daily, rapidly increasing to 48mg daily when the maximum acceptable dose was 18mg daily.

#### **RE-EMERGENCE OF ORIGINAL SYMPTOMS?**

Stopping benzodiazepines can cause withdrawal symptoms; BZD can relieve the withdrawal symptoms of other addictive drugs, such as barbiturates and alcohol, even though they are not precisely the same; and benzodiazepine antagonists produce withdrawal in experimental animals.<sup>77</sup> That is, benzodiazepines definitely are addictive.

But there is more to it than theoretical proof. Most alleged withdrawal symptoms are not part of the original problem. The turmoil of *milieu interieur* in the withdrawing user is not like anything they have ever had before.

Rebound anxiety may be much worse than the original anxiety – if there was original anxiety. Many symptoms are new: perceptual distortions, sensory hyperacuity, muscle twitching and paraesthesia, fits, hallucinations, etc., etc. Original symptoms are prone to continue but BZD withdrawal symptoms decline. Babies whose mothers were addicted go into withdrawal.<sup>78</sup> Patients do not show gross search behaviour, nevertheless, they are unwilling to give up their drugs.

That is, they are addicted.<sup>79</sup>

Despite these copious proofs, some authorities minimise withdrawal by ingenious finagles. 'In behavioural terms, this could be explained as a period of learning to cope with stress after a prolonged period in which coping has been carried out by an erogenous drug.'80 Plausible, very plausible - but what about the patients whose coping skills were adequate to start with?

Many patients are prescribed them for bereavement, illness, change in marital status or even in abode without regard to their capacity to deal with these stressors.<sup>81</sup> Barbara Gordon was prescribed Valium for a back injury years before she received it for anxiety.<sup>82</sup> There is no justification for simply assuming prior anxiety or failure to cope.

The fact that many patients can get by with very simple counselling<sup>83</sup> suggests that people are better able to cope than doctors think they are. Not only that, patients are more satisfied with the chat than the prescription. This suggests that patients are not looking for a quick fix and welcome the opportunity to cope alone with a bit of help from their doctor.

I was always impressed with the coping skills among the thirty or so individuals I met at the support group. TRANX did not separate those who were only thinking about withdrawing from those who were in voluntary withdrawal and perhaps suffering greatly. The latter group often refrained from asking for support with gross symptoms in case they frightened someone who had not yet decided to withdraw.

Some of the most supportive interaction occurred between individuals after the main group session. The group was constructively altruistic.

I do not believe that these skills had been learned in the group itself because it mostly offered support and simple relaxation techniques - not problem solving or other skills. Terri advised us not to get up and scrub the floors when we awoke at two o'clock in the morning tormented by restless energy. Will showed us how to abort panic attacks by breathing into our cupped hands. Most of us clearly had our own ways of handling problems - not the stereotyped routines of something learned in a group.

#### TRUE WITHDRAWAL

Withdrawal varies between one patient and another: a combination of samples revealed that 55 per cent have no symptoms, 16 per cent relapse to their original symptoms which then continue, 15 per cent have low grade symptoms (rebound), and 14 per cent have severe symptoms (recoil). Both rebound and recoil sufferers recover in time.<sup>84</sup>

I drank compulsively and urinated to match.

I have always tried to drink a lot of water in the belief that dilute urine is less likely to harbour the bacteria that encourage cystitis. Now I am no longer in control of my thirst - all I can do is impose a routine on it. I work at my desk until it becomes nearly intolerable, which is about once an hour Then I saunter down the corridor to the tearoom for a couple of glasses of water. These are profoundly private moments that I imbue with ritual staring out of the window as I drink, seeing myself as Victor of Aveyron in Truffaut's Wild Child: totally alone, able to commune with the outside world but not to communicate - except in the most superficial way - with my species.

Then I trot upstairs and urinate. The tearoom is at the front of the building the toilets at the back so I vary the routine, now using the front stairs - now the back, now using the third-floor toilet - now the first, now using the first-floor corridor, where management looms, now crossing the busy third floor where patient women play keyboards endlessly. The routine minimises the disruption of polydypsia/polyuria but it has a further use. It controls the restlessness that makes sitting in one place a torment.

The phenomenon is well reported in the literature but I never heard it complained of by sufferers, perhaps out of delicacy but perhaps because they did not identify it as a symptom. Not associating one thing with another, Narelle called her compulsive piddling 'cystitis' but she did not see that her endless tea-drinking was part of the same symptom.

Trivial you say? Would you wish it on a brain surgeon? on a train driver? Would you want it yourself?

### ADDICTION SICKNESS, PSEUDO WITHDRAWAL, AND PERMANENT WITHDRAWAL

The BZD fallacy that I find most obscene is the medical claim that users are well and happy until they try to stop. This, of course, is a necessary premise for the claim that some patients cannot function without their pills and should be maintained on them.

The claim also relates to the false analogies with other addictive drugs. And, inevitably, it is used to excuse diagnostic nihilism: 'Benzodiazepine dependence is difficult to identify because most dependent patients only show evidence of addictive behaviour after their drugs are stopped.'85 Doctors need to unlearn the stereotype of addictive behaviour based on illicit drugs like heroin and see how benzo junkies actually behave.

The picture of the happily maintained user ignores a basic and unpalatable fact: most patients complain of *worsening* symptoms while on the drugs. They are then given dose increases, other BZDs, other psychotropic drugs, or other investigations. Addiction sickness is different from the original problem and includes many symptoms of withdrawal. I have not been able to decide whether it is accompanied by or followed by tolerance but I am absolutely certain that happy maintenance is a myth.

Perhaps I suffered addiction sickness more dramatically than some survivors because I was taking Ativan/lorazepam, which is generally acknowledged to be among the more savage (and the most litigated) of the benzos. In any case, my symptoms were by no means confined to the abstinence period.

# Some Symptoms Persisting Both On and Off Ativan (roughly Autumn 1983 to Autumn 1990)

- muscular stiffness
- speeding up and slowing down
- blurred vision
- bruising
- rash
- insomnia
- unpredictable libido
- tongue-tiedness

# Some Symptoms More Characteristic of Withdrawal From 2.5mg Daily Through 1.25mg Daily to Zero (roughly Autumn 1988 to Autumn 1989)

- reckless courage
- hallucinations
- withdrawal psychosis
- ground moving
- paranoia
- flashbacks
- learning complex skill (word processing) unnecessarily difficult
- poor memory
- pain
- sensitivity to sound, light, touch and temperature
- muscular weakness
- increased co-ordination and pleasure in using the large muscles
- conjunctivitis
- anorexia
- tinnitus

• agoraphobia/claustrophobia.

Some investigators, observing that patients complain of symptoms when they are led to believe they are getting placebo but are still getting BZD and their blood shows therapeutic levels of BZD, have called their symptoms 'pseudo-withdrawal'.<sup>86</sup> Others are inclined to treat this as bona fide withdrawal due to tolerance"<sup>87</sup> - the condition that would lead to search behaviour and increased doses if the patient were taking street drugs.

Some short-acting BZDs, such as lorazepam and alprazolam have such a short half-life that a mini-withdrawal occurs between doses and a missed dose can lead to intense distress in hours. Survivors in the support group habitually speak of being in permanent withdrawal even while they are still on their pills.

#### **HOW LONG DOES WITHDRAWAL LAST?**

Dr. Shy, along with quite a few other medicos, firmly believes that BZD withdrawal lasts ten days. This fallacy may derive from the unjustified comparison with nicotine. Alcohol withdrawal takes about one week; amphetamines from twenty-four hours to several months; cocaine can be given up in about ninety days; the worst of heroin is over in seventy-two to ninety-six hours although some unpleasantness lasts for weeks. The notion that BZD withdrawal is short is most likely an artefact of health insurance policies that refund ten days detoxification in hospital. The pills are withdrawn from the patients but the patients are not withdrawn from the pills.

Joy was a widow with two young-adult sons. She had permanent back pain from a fused disc following childbirth. She was put on benzos when her husband died and withdrawn in hospital two years later. Her first withdrawal attempt failed because the hospital transferred her from one benzodiazepine to another of a different name.

Her sons, who accompanied her to TRANX said that she was given a choice between hospital withdrawal and slow withdrawal. She feels that she was coerced into accepting rapid withdrawal because the doctors hoped to uncover a latent depression. (Alert readers are no doubt asking how they planned to distinguish between latent depression, newly revealed, and withdrawal depression.)

On the way home from hospital, Joy transferred from the front seat of the car to the back because she was hallucinating so badly. With her doctor's encouragement, she returned to driving immediately, although 'it was scary at first because the scenery was going faster than the car.'

The difficulty of dealing with permanent pain and medical refusal to accept the continuing reality of withdrawal proved too much for Joy.

While I was writing this book, she killed herself by overdose, the second member of the support group who attended this hospital to suicide.<sup>89</sup>

Realistic estimates of BZD withdrawal times range from several months, 90 to up to a year, 91 and months or years. 92 My physical symptoms took very roughly eighteen months to begin to abate and psychological ones took another eighteen but there are times when I feel that one never recovers. Usually I tell people that the way out is the same as the way in-in bold, round figures, five years on, five years off.

The social harms may be irreparable. The woman who marries at twenty without a marketable skill, is put onto BZD after her first pregnancy and kept on them for twenty-three years, through two more pregnancies and divorce, has very little hope of getting off welfare.

This is a summary of symptoms for one day (25 December 1988) approximately two months into zero withdrawal. Symptoms varied from day to day, but the incessant disruption became too pestiferous even for my diarist leanings, so I stopped recording them.

- sensation of light cobwebs around nose this is an improvement on heavy cobwebs over whole face.
- sensation of button-hole stitching or chewing around nostrils and ears no longer sharply painful, more as under local anaesthetic.
- sharp stab in right leg during day (during addiction these stabs were mainly at night); not enough to produce reactive jerk.
- rippling tension in thigh and calf muscles could be described as 'things crawling over me' but deeper than a skin sensation. Required conscious control and repositioning to avoid embarrassing tics and jerks.
- frostbite burning and freezing in right lower leg, with numbness and tingling and sensation of swelling when none present: could sometimes reach intensity of distressing pressure and pain.
- drilling pain behind ears.
- sensation of wetness on face like a panda's markings around eyes and mouth.
- blurred vision and difficulty reading.
- steel helmet headache (briefly).
- intense anxiety.
- exacerbation of arthritic pain.
- exhaustion.

Certain tasks, such as using a motor mower on a very hot day, exacerbated the symptoms.

#### MANAGING WITHDRAWAL

Although some psychiatrists allege that patients with dependent personalities are harder or even impossible to withdraw, Dr. Ashton concludes from her sample of three hundred patients that anyone can be withdrawn successfully - even people over sixty-five. <sup>93</sup> Some observers find that older patients are easier to withdraw than younger ones. <sup>94</sup>

These opinions conflict with the pessimistic consensus that older people have little hope of withdrawal yet good anecdotal evidence from both England and Australia also suggests that nursing home populations have been withdrawn by a simple change of policy: no more tranquillisers.

My own impression - and I cannot justify it - is that the optimistic prognoses are based on individuals who are alert enough to recognise what their problem is and to volunteer for withdrawal while the pessimistic ones are drawn from multi problem individuals. I have observed one sprightly septuagenarian withdrawing slowly at TRANX and two dear friends, also in their seventies, who are hopelessly addicted.

TRANX recommends that withdrawal cannot be too slow - specifically, they suggest a ten per cent reduction every ten days or whenever the patient can manage it.<sup>95</sup> Dr. Jean Lenane suggests that there is a choice between more severe symptoms for a shorter time or less severe symptoms for a longer time - that is, a one-sixth reduction every three days or one-sixth every two weeks.<sup>96</sup>

Patients on short-acting BZDs may prefer converting to an equivalent dose of diazepam or a liquid BZD and come off slowly, 97 rather like paying off a debt in five-cent coins instead of five-dollar bills.

Dr. Ashton recommends these drugs for abstainers who cannot endure withdrawal: promethazine, 50-100mg two hours before bed; propanolol 20-40mg two or three times daily controls tremor, palpitations, muscle spasm and possibly panic attacks; sedative tricyclic antidepressants may be used for depression; buspirone is contraindicated, as is caffeine and alcohol.<sup>98</sup>

I, personally, recommend tryptophan: its sleep is not quite so good as the sleep of TM or of orgasm but it is better than the sleep of BZDs. Most of the alternative therapies - yoga, relaxation, massage, breathing exercises, aerobics, and diet - are helpful. At the very least, they are a constructive and harmless distraction that will become a foundation for a new, post-tranquilliser existence.

In order to save face, some doctors who acknowledge BZD addiction will persist in attributing some of the symptoms to another disorder requiring medication.

Caitlin, six months into withdrawal after fire years on 75mg Ativan and still wearing the BZD face, was diagnosed as having a depressive illness and put on tricyclics. Anyone in her position might well be depressed - she had been forced to leave university, lost her stop-gap job, her parents were upset and she looked so dreadful that her boyfriend asked her to use make-up.

Depression is a healthy and realistic response to her situation but should not be equated with illness and should not be medicated. I believe doctors must be absolutely meticulous about prescribing any further psychotropic drugs until the patient clearly is out of withdrawal.

Getting sick is so rapid and getting well is so slow that if I described my experience in anything like documentary detail, it would make a monotonous and boring story. Instead, let me offer the epiphany of falling over.

I have said that I became clumsy on Ativan and began to scuff my shoes and fall over. One day, in winter 1984, on 2.5mg Ativan daily, I left the East Coburg tram at the Rising Sun corner carrying a light but large box containing a woolly mattress underlay for my worsening - or so I thought - arthritis. I found myself subsiding backwards over the tail of the pedestrian safety zone and being hoisted to my feet by a prompt and strong-armed tram-traveller. (Thank you, wherever you are!)

Normally, one feels winded, shaken, and embarrassed by such a fall but I felt ... nothing. Normally, one knows one is falling and tries to save oneself. I felt, as it were, in slow motion, like a puppet whose strings have been dropped.

Four years later, in zero withdrawal I was trotting between Dr. Manners and his friend, who was soon to be elevated to a chair of pharmacology. We were on our way to a good pizza and a good chat.

Suddenly, I tripped on the root of a mulberry tree that was tearing up an old pavement where Carlton slopes down into Fitzroy. Taking one arm each, and without interrupting our conversation, the colleagues set me upright.

Still talking Dr. Manners popped my hat on (back to front) and Dr. Soontobe straightened the wing of my glasses where they had connected with the pavement. I was so near to going arse over tip that the top of my left shoulder was bruised. My

skirt had a crushed mulberry in every pleat so that I went around smelling like summer pudding for the rest of the day. I was winded but not embarrassed. For the moment, and at intervals of chewing pizza, I stared happily at my palms: the heels were red and grazed where I bad flung my hands out to save myself.

While I was still on 2.5mg Ativan, people looked at my dragging gait, breathlessness and sorrowful face and whispered words like 'moribund' ' About two months into zero withdrawal, they began to tell me that I was looking better. One friend said I had improved two hundred percent between autumn and winter of zero withdrawal Dr. Manners said I had improved a million per cent even in the month between our first and second meeting. They kept on saying it for years. As bizarre symptoms abated and lost capacities returned, life seemed to be a series of happy milestones.

As I saw myself getting better, even in such a little thing as falling over, I nearly wept tears of joy. When I came to research this book, and discovered how unnecessary it had all been, I nearly wept tears of rage.

## CHAPTER 8 CASTEL SAN ANGELO

Anyone who goes to a psychiatrist needs his head examined.

Samuel Goldwyn

I am standing inside my own mouth - an immense cavern lit from somewhere behind and above me by an unseen tungsten light. I do not see my tongue but the floor of my mouth seems to be that plain, brown heavy-duty linoleum used in old offices and institutions. The light, obviously, is not enough to illuminate the vault, which soars above and away from me. I sense, rather than see, the presence of others; I never do see them. Buffeted against stone walls, I recall the crowded narrow staircase of Castel San Angelo in an affluent Roman summer. My shoulders bump along blocks of stone bellying out almost as big as I am. I do not feel fear but I would prefer not to be imprisoned.

Somehow, the space is shrinking and the I/eye becomes my invisible but feeling tongue; I could not see it because it is seeing for me; the great blocks are my teeth. I can feel every cavity, every filling every irregularity inside my mouth. My tongue has become eyes and all there is to see is teeth. I cannot switch off the dreadful consciousness of inside teeth. I dread my future life if I am to be locked into my sense of touch like this - like the man with X-ray eyes, who could never stop looking because his eyes saw through their lids. I shall have to ask the dentist to polish my fillings - I cannot bear to live with this detailed and trivial consciousness much longer.

Somehow, I am again in the dark but do not know where in the dark I am. I struggle upwards and find the light-switch next to the thermostat that ticks like a comforting metronome. I am sleeping in the livingroom because the street noise in the front bedroom has been intolerable for many nights. The light that instantly creates the room with serried bookcases is the same soft tungsten spread in the same dome as in my ... it was not a dream! It was unlike any dream I have ever experienced! I have to call it a hallucination.

For a small age, my tongue became the sensate focus of my whole being and even after I escaped the cavern, it still dominated my other senses!

During the year when I had been ailing, none of the innumerable tests for somatic symptoms had revealed anything. I was extremely

reluctant to see a psychiatrist for the misery because I was absolutely convinced my current problems were physical and that my anxieties were rational responses to my real situation. But the hallucination suggested that I was up to my ankles in lunacy and that I ought to seek help in case the flood rose and I and my reputation should be swept away. I had suspected manic depression for ten years but had been frustrated in my attempts to get lithium. The hallucination convinced me that I must make another attempt.

Unable to find any psychiatrist available in less than six weeks, I made appointments with three in the hope that one or other might have a cancellation; then I settled down to survive the waiting. The first to slot me in was a wonderful woman but she did not use any form of chemical even lithium which is not really a drug. Grateful for her kindness and good sense, I wait for the second.

A man has more chance of being a hero to his tailor than a doctor has of being a hero to his nurses. You have a good name among nurses: 'He doesn't say much,' said Bobbie, 'nothing at all really. If you laugh at his awful socks, he shrivels right up. But he is kind. Very kind and very patient. But he does follow the medical model.'

Your voice, when I hear it on the telephone, is low. And soft. And dry. And expressive. And competent. I cannot tell if I am listening to a young old man or an old young man. I might be listening to a Hobbit.

'Enter from the west,' you say, 'go across the car park to the revolving door, take the lift to the eleventh floor and turn left.'

There I sit among regimented, shabby, hospital chairs and read my diary.

'Mrs. Kerfoops?' You were behind my left shoulder. 'I am Dr. Blank.' I never see your face, then - or ever. You are off down the corridor before I have time to look up.

'Surely,' I think, 'surely anyone so old-fashioned as to introduce himself as "Dr. Blank" will have an old-fashioned respect for patients?' My sanguine heart leaps out of my chest and shusses away down the corridor on the tails of your stiff white coat.

Your little room is as ambiguous as your voice. Obviously this is not your main practice - it has the austere tidiness of a space rarely used. To the right of the door is a child-sized table and chairs with a

few bright educational toys and a child's painting is stuck on that wall. The work of your own child or a juvenile patient? I want to look at it more closely but I don't know you well enough to browse. The main furniture is the same cheap, anonymous, plain stuff as the waiting room but the odds and ends express personal care and adventurous preferences. Not the conventional doctor's room.

The black Nigerian masks were made before the tourist trade eroded local craftsmanship. There are only a dozen or so books - mostly hyperexpensive, anonymous medical texts but I recognise the two-volume edition on the end. I have it myself: the notebooks of Simone Weil. A terracotta aggie pipe filled with ruddy kangaroo paw gives a comically happy touch to this cupboard.

The desk is clear except for a crazed millefiori paperweight, a foolscap pad and a Mont Blanc magnum that is the only luxury item in the room. For you, it is just a pen with a large capacity. The paperweight must be a family treasure - it does not fit in with the other things and no one would buy an object in such bad condition.

Promising ... instead of peering up at you across a polished barrier I am sitting at the side of your desk.

You read the envelope before you read the referral. I read your intelligence in the mobile creases between your eyebrows.

Across the top, my scribbled notes of your instructions: 'Enter from west ... across car park ... revolving door ... turn left.'

Across the bottom, my agenda for our consultation: 'aminophylline insomnia benzo symptoms cycles.'

When you finish with the letter, you say quietly: 'Well, Mrs. Kerfoops, tell me about your benzodiazepine abuse.'

I have seen enough Hollywood movies to know that it is most unwise for a female patient to bite, slap, shake, thump, scratch, spit at, piss on the boot of or otherwise chastise a psychiatrist - especially when the consultation takes place in a hospital and he wears a white coat. I swallow the affront, drop my eyes and shake my head with the sanctimonious stubbornness of a child falsely accused.

'No! I am the abused, not the abuser.'

Then I give you the usual outline: `1977, began taking Nuelin ... called it "the fear", Virginia Woolf called it "the horrors".'

I am not sure of you ... do I need to say that Kafka was anxious? Woolf manic-depressive? You are imperturbable and I decide to fall on you with the full weight of my anguish ... to speak as my intelligent self and not as a supplicant patient 'Amitriptyline and Valium .. came off ... biofeedback ... 1983 Ativan ... stink. . .'

'Could other people smell it?'

My anger flickers. I cannot bear a repetition of Dr. Dickhead. 'It wasn't hallucination! Dozens of people smelled it! And commented! It wasn't hallucination!'

You waver slightly under my buffeting like a tethered blind. You really are very gentle.

'Could ordinary people smell it? or just benzodiazepine users?'

I am immediately calmed. It is the first question from any doctor that reveals any familiarity with addiction. You know what you're doing. It whets my expectations.

'Falling over ... stroke ... Does "ischaemic" take a hard or a soft c"?'

'Iskeemic,' you breathe, without looking up from your pad. Your large, even, fluent, black handwriting is beginning to fill the first page.

'Joint pains ... 1988 came off ... horrors ... more pain ... spontaneous bruising ... hallucinations ... agoraphobia ... claustrophobia ... paranoia . . .'

'What do you mean by "paranoia"?"

'The same thing that you mean,' I say, laughing.

'Tell me.'

I tell you.

`Cobwebs ... chewing. . . wetness ... blurred vision ... tinnitus ... pain. . .'

By now I am snuffling with self pity, and habit, and relief I am in a safe place. I can expose my misery. I take my glasses off and put them back on and fold them up and unfold them. I am pleased to see that you do not keep a box of tissues on your desk. You are not that kind of doctor - but just the same, it would be chivalrous to pass me the wastepaper basket.

Your questions are non-invasive. You must have gone to a workshop in communication skills but I sense from your slight startles and recoils that you're not confident that you've mastered this new way of consulting. Or perhaps you are apprehensive at being in a confined space with twelve years of accumulated pain and rage.

The contempt I feel for all the inept doctors spills over a little on you. Your willingness to learn a new skill makes them look villainous. You are a skilled member of a villainous profession, Dr. Blank!

There is something the matter with you and there is something different the matter with me.

I ask about aminophylline.

'It is common knowledge that it produces a wide range of very [blip] reactions; very [blip].'

I ask about insomnia. You have condemned megadoses of vitamins as 'entirely unjustified' with the pudeur of a maiden lady speaking about excessive use of the sexual function among the proletariat. But then ...

'Tryptophan is the treatment of choice. The practice here is to give up to fifteen grams in severe mania. You would feel very [blip] very [blip].' Fifteen grams is thirty tablets and not on the national health! If one is severely manic - seven dollars for a night's good sleep! Perhaps, in the asylum, he had lost touch with the world outside where people paid for things with money.

You stare blankly at me, a little perplexed by this mundane challenge.

'How do you know megadoses won't have side effects? - look at pyridoxine!'

Again you seem blank. I refer you to Oliver Sacks, because I can't remember the journal details.

So long as you are communicating through me with your pad, you are painstaking and patient. You question me simply and methodically and answer my questions briefly, frankly and distantly - all in your soft young-old voice. But when you have to speak to me direct, especially to give advice - in other words, to play doctor to my patient - you become as pompous as a Stalinist agitator.

You use constructions that absolve you from personal responsibility . . . 'It is common knowledge that . . .' 'The practice here is to . . .'

You rarely say 'I . . .'

Your voice becomes orotund. You use unnecessary latinisms ... develop a curious echolalia . . . 'an expert in affective disorder affective disorder.' Very [blip] reactions very [blip].'

You have been described to me as humourless but you are just pathologically shy. I wonder how anyone can be as shy as you and still practice medicine. The stiff white coat is more than a uniform, it is also your cuirasse.

I am terribly speeded up - as distressed now as you are calm. I cannot control the volume of my voice. I hear myself growling like an articulate animal. I can find no place between absolute control with an appearance of normalcy and inchoate grief. Every so often a piece drops out of your conversation, as neatly and totally as if it had been deleted from a computer screen. Mostly, I recognise the sense of what you say.

It doesn't really matter whether aminophylline produces 'bizarre,' 'peculiar' or 'strange' side effects or whether tryptophan will make me 'muzzy', 'woozy' or 'sleepy' - I understand that aminophylline is notorious and that large doses of tryptophan are hard to wake up from.

I don't tell you about the deletions because I am so habituated to feeling awful that I have come to notice my withdrawal symptoms without paying any special attention to them. If I want ultimate relief from the symptoms, I mustn't let them distract me now.

In any case, I cannot speak of trivia. There is no time. I feel as if I am caught up in a punishing game of squash. The ball must be kept moving, despite my fatigue. My head ricochets off your questions. I want desperately to slow down but it is impossible to ask for quarter.

You are the doctor, I am the patient and we are working together for my good.

I am either too far away from you or too close. The room is either too dark or the light from the west-facing window is too dazzling. I am conscious that I am listening to you while looking away from you. I try strenuously to meet your eyes.

Looking into your face, I am appalled by your innocence and your glasses - such thick lenses for so young a man! I find myself hurtling towards them. I can't stop. I wonder what it will feel like. I hope you won't mind. It is an impertinence. I am inside your glasses and ... there is nothing there ...! I am through Mach 1.01 and you don't notice.

You are subtly at home in your body. You have no small talk, but fine gestures speak for you. You frown delicately, purse your lips, briefly wrinkle one eyebrow, shrug rapidly, sigh and flex your shoulders at the end of an answer. Before you ask the next questions, I already know when I have given you enough details ...

'And what happened to that marriage?'

'It ended in divorce.'

'Divorce! Oh - but divorce ... ? Divorce . . .' This is no echolalia - it is genuine pain.

I am not sure whether you are trying to tell me that the Holy Father takes a dim view of women like me; or maybe you think that divorce is an extreme reaction to a bit of old drug addiction; perhaps you simply mean that it is an unfortunate business.

We stare sadly at each other for a moment, then we are off again. I fear to bruise your delicacy. I prefer not to expose your simplicity to my complicated life.

I do not want to hear your soft, pained voice saying 'Two divorces! Oh but two ...?' 'Three abortions! Oh but three ...?' 'Ex-nuptial ...?' 'Standing up in a hammock ...!' 'Seventy-nine ...!' 'With a pedophile! Oh ... with a pedophile?'

I pelt you with five or six obvious explanations for my divorce. You demur when I say that benzos were a factor in the disintegration of my marriage. Glancing towards your pad and pointing nicely with your chin, you say 'There's a lot of stuff there!'

You ask wonderfully productive questions.

'What is the most important thing you hope to achieve this year?'

I discard the tired answer – 'Please, Dr. Blank, sir, I want to get better.' 'I am going to sue the psychiatrist!' The resolve in my voice surprises me. (It is a feature of my new condition, that I often don't know what I'm going to say until I've said it - although, having said it, I usually find that it is true.)

You are visibly buffeted but recover quickly. 'Why?'

I snort with contempt, stare at you and say nothing. You know why ... I know that you know why ... You know that I know that you ...

'You must tell me.'

So the squash game continues. I give you a rundown on the suffering I have seen in the support group. On WHO statistics of addiction. Of the marketing procedures used by the drug companies. On the educational value of test cases. When you are satisfied that I have come clean about my motives for suing the doctor, you face me and say unctuously, 'I do not say that you should or should not undertake this course of action but I would counsel you about the cost to you the cost to you . . .'

Exhausted, even by your benign questioning, I dread the battering I will face from lawyers. I shall need more sensitive support than my lawyer can give.

'I should like to pursue that proposition.' I am beginning to imitate your Latinisms, like a hostess who blows her nose in her napkin so that her uncouth guest won't feel out of place.

You look at me with a little, crooked, secret, melancholy and self important smile. 'You might sue me!'

When I asked Dr. Manners about you, he said 'Competent. Highly competent. But humourless.' Now, I have seen you smile and I know he was not quite right. You are shy and well defended but you have just let me peep at a genuine *galgen humor*.

Then you address your writing tablet once more.

'Who is the most important person in your life?' You use the word 'person' awkwardly but with such sincerity that it reveals a firm commitment to non-sexist language and a non-judgmental view of sexual preferences.

I am, so far as I can be, a considerate patient. At the end of the hour, not to discommode you, I begin to prepare for the street. I look at my watch and at your face. You put down your pen and swivel your chair to face me, ignoring my repeated signals, and engage me in desultory conversation about my childhood, my relationships and so on and so forth. I hear your third voice: audible but wooden and flat.

You look at me with the solemn patience of a kelpie who has learned that it is sometimes hard to tell sheep from goats. You are not absolutely sure that I won't rear up and menace you with the horns of an Angora billy. But what if I should be neither a sheep nor a goat? what if I were something quite else - a llama, for instance?

It takes me a while to realise you are doing something I have never seen a psychiatrist do. Psychiatrists usually impose labels. You, gentle Dr. Blank, are making a diagnosis!

You keep me for a further half hour. Then I realise that I took the two thirty slot because I have an appointment elsewhere at four. Just as I am gathering my initiative to interrupt the chit chat, you conclude that the transmogrification is not going to happen. You allow me to return to the flock.

'I take it you have [blip] the literature?'

I risk a guess on your meaning. 'I have read very little. Dr. Manners has promised to put some books and papers together for me.' That reply seems satisfactory.

`[blip] help you.' you say formally.

This time my flickering rage is directed at you. I want to tell you that you haven't helped me at all! we haven't even got down to a remedy for benzo symptoms! we haven't discussed the cycles or lithium and I'm never going to get a taxi on Friday afternoon!

But, as I admit to myself that I cannot sustain rage against a gentle soul, you ask one last casual question, glancing down with the memory

of a smile at the corners of your mouth. (Kelpies often seem to smile). No other doctor has asked me this in all the twelve years of my malady:

'Is today a good day or a bad day?'.

'A good day,' I say, belied by shine on my nose and tearful heat in my cheeks, 'but we have been discussing bad things!'

To show that I have forgiven you for not helping me, I say that you have been very civilized before hurling myself into the street.

For weeks after, I was obsessed by my experience with you. I could not believe that a person of your good taste and good sense would leave books unprotected on a window ledge in a west-facing room. I was desperately annoyed at not being able to visualize your eyes: what colour were they? how could there be nothing behind your spectacles? More playfully, I explored purely intellectual problems - was I two people when I stood with my back to the lenses? how could a person be squeezed inside the lenses and still see the full width of the head? where was the bridge of the glasses? where was the bridge of your nose? How did I get out, back, down from up in there?

I remembered you as sitting both at the end of a dark tunnel and against a bright window. Actually, for most of the time, we were about a meter apart and the west-facing window was very bright in the early afternoon. Despite the fact that we were sitting at your desk for all but a few seconds of the ninety minutes I spent with you, I remembered myself typically as looking down on you from behind your left shoulder - where I stood when I dropped sodden kleenex in your wastepaper basket - although I could not have been there for more than ten seconds. I visualized you typically as standing, looking down at me and talking as you did when you showed me out - but this could not have happened for more than a half a minute.

The visual distortions were quite similar to those I experienced with Dr. Dinkum - although with you I never lost the ability to read print and had no double vision.

I began to ponder a new and distasteful question: could my distortions be just what ordinary people experience during periods of stress? Had my previous systematic view of my world been the view of some sort of freak and is fragmented vision the norm?

I was a little comforted by my capacity to monitor the situation rationally even when my perception was short-circuiting - just as I had known that I was reacting in a paranoid way with Dr. Dinkum and controlled my impulses. This showed that a lot of valuable circuits were functioning normally and gave me confidence in my interpretation of events.

My inability to call up your eyes and the barbarism of the unprotected books distressed me as much as the more practical questions. Why hadn't you discussed remedies for the symptoms? Why hadn't you given me another appointment? or referred me on?

I became obsessed with replays of childhood miseries. Insults and conflicts that I had long believed assimilated billowed up like gas from a lightly buried corpse. I wanted to ask if you knew of anyone who had ever been freed from those sorts of insults. Had the time come to give up hope and accept my psychic suffering as I had accepted my rotting lungs and crooked spine?

The split between the assertiveness of my public self and the supine private me, while not exactly a new discovery, became problematic. While I was married, my private self was in my husband's purview. The divorce meant that I had almost no access to anyone who knew that self, which now seemed a wanton luxury. Obviously, reconciling my two selves would be a major psychological task - perhaps for the rest of my life.

I was sincerely curious about what part Ativan had played in the breakdown of my marriage.

I wanted to ask how I could integrate the experience of benzodiazepines into my life in the real world? What sort of person had I become? How was I to conduct myself?

I felt as if I had returned from an extraordinary journey, bearing arcane knowledge that separated me from other human beings. I had seen the banality of evil, not merely in the wickedness, cruelty and stupidity or wicked cruelty or cruel stupidity of certain doctors but in the everyday conduct of ordinary people.

If I was oppressed by the discovery that the lack of a moral sense is not confined to a few psychopaths but is endemic, I was quite stricken by a feeling that I now had knowledge of good and evil that I had never before known and that my unique understanding set me apart from humanity.

A convent seemed to be the only solution for a person of my state but I was not religious. I saw myself as a self-contained recluse - going to work during the day and living quietly at night in darkened rooms. In my eagerness to plan the rest of my life, I borrowed Sheila Cassidy's book about her Chilean imprisonment but it told me nothing. Dr. Cassidy had been alienated from her peers and her expected role before she was imprisoned. As far as I could tell from such a pitifully shallow work, the experience of torture had not alienated her from her sense of self.

My value system had undergone a massive shift: previously I had lived among Millian humanity; now I was preparing to flee from Hobbesian Man. From thinking that people are generally rational, well-intentioned and capable of improvement, I had come to believe that almost no-one is any of those things. This entailed a corresponding shift in my disposition towards others.

I had always been forgiving. As a thirteen-year-old, I had discovered the practice of analyzing human motives in the agony columns of the first *Woman's Day*. I had concluded that to understand all is not to forgive all but to see that there is nothing to forgive. Forgiveness is irrelevant because everything is determined (although amenable to change). I had found extenuating circumstances for everyone. Now I began to operate from a moral position, not a psychological one: nothing is excusable, we are always able to choose good over evil but most prefer not to. I constantly had to stop myself using the words 'shark', 'baboon', 'mongrel', 'skunk', 'rat', and 'tapeworm' pejoratively. Animals don't prey on their own kind. I still have difficulty reminding myself that all doctors are not tarred with the one brush.

The human potential movement has elaborated the policy of hating the sin and loving the sinner into a program in which people who sin are not labeled sinners. Certainly, they have committed sin(s). Apart from this, they are ordinary human beings who should be treated like anyone else.

Thus, one must not call a man who urinates in a public telephone box a yahoo: one must say he has done a yahooey thing. This position has obvious benefits for therapy: in order to direct people toward a more perfect development of their humanity, we must believe that it exists. And how better to convince ourselves than by labelling them 'human'? As a general moral principle, however, it is almost too silly to refute. Consider, if you will, the Yorkshire Ripper, or Mr. Stinky, or the Anita Cobbey murderers. But my quarrel was not with the unique monster. It was with the housewife who cleans her beleagered neighbour's toilet in order to size up and gossip about her poor taste in antiques; or with the woman who unwraps a gift in order to assess its value before thanking the donor while, at the same time, confiding her distress over her husband who 'thinks of nothing but money!'

When I thought of Dr. Blank I understood Josef Mengele.

I felt raped. Iatragenic poisoning constitutes an invasion of privacy quite as much as unsought intercourse. I had never strongly shared feminist concern with rape because I felt that women should not define themselves by their vaginas. Our being should not reside between our legs. To say that one's whole being could be shattered by penetration of the sex organs was to accept cultural definitions of Woman as a cunt on legs. I wanted women to have an identity outside their anatomy. For me, the menace of a physical attack was different.

I was anxious about what was between my ears - that I might be punched or kicked in the head or hit my head in falling and find myself brain-damaged. In the benzodiazepine experience, the catastrophe that I most feared had happened!

I examined these issues in the moments before falling asleep and during bouts of insomnia. They occupied me under the shower, in the train and when I stood in queues at the bank. While I was pursuing these problems with manic urgency, I addressed all my dissertations to you. Always and only to you.

When I had begun the search for lithium, I had been confident that I should never again put up with that fatuous and futile process known as psychotherapy. In these weeks, I believed that I had lots to talk about and that in my racing private mind (as distinct from the public mind that worked for money or functioned creatively), I was talking only to you. Always and only to you.

Sometimes I trust my fragile self to your kelpie self and at other times, I confront orotund Dr. Blank like Florence Nightingale with the doctors of Scutari. I know that if I become your patient, I shall have placed myself in the power of a conservative practitioner of conventional medicine. Sooner or later I shall be obliged to confront it. 'And you, Dr.

Blank, what is your complicity in all this? How often do you prescribe benzos? Why? To whom? What instructions do you give your patients? How many addicts have you created? How many times have you let patients escape follow up? What responsibility do you own for your conduct?'

Before, when I used to have good days and bad days, I was always free to rest and could escape to bed. Now that I was working for a boss, I had to be in my office and to socialise every day. This was exhausting. I could get through the bad days passably but I found that I was no longer recuperating on the good ones. The bad days were beginning to eat up the good. I led an obsessively orderly and regular life but I suffered from the fatigue that comes from pasting films of cheer over cracks of anguish. This recognition made me ask for another appointment with you.

My file had arrived from the hospital under Freedom of Information but the photocopying was awful. If they were trying to hide something, they could hardly have done it more illegibly. Sitting once more in the regimented waiting room with the aspidistra polished by nuns, nursing the heavy folder, I wondered if I would be able to recognise you from the fragments that I remember. I did - from your white coat and the way you sped along the corridor holding a briefcase with a broken clasp. Your wispy hair, carefully tidied, tells me that you are youthful old and not weary young.

Throughout my illness, I had developed best-case/worst-case scenarios to organise my life and to conserve the energy invested in waiting for future developments. This was part of the dichotomous way of living that I had perfected in early withdrawal. My best case is: 'you help me'. The worst is: 'you refer me on'.

It is worst case.

Your pad and pen are neat on your desk but you slump in your chair. I shall not see your best self sheltering behind your writing pad. You peer at me through steepled fingers.

'You wanted to see me, Mrs. Kerfoops?'

I am already feeling nauseous.

You ask me what I want. I steady my stomach. I am succinct.

'I have been thinking about everything and I want you to manage my withdrawal, give me lithium, counsel me during my court case and talk about various problems.'

'I cannot help you, Mrs. Kerfoops. I indicated this to you on the occasion of our previous consultation.'

('You might sue me! [blip] help you')

I hate the orotund you, calculate how rapidly I can stop this charade and ask for a referral. Stoically, I tidy my file and pack it in my bag while we talk.

Considering its ominous beginning, our talk is amazingly rational and gentle - you are your kelpie self again, attending to your cure of sheep.

I experience, for the first time, the frustration and despair that I have heard about in the support group - but I know that I am being let down gently. You deny that I am suffering from withdrawal symptoms but you do not blame me.

'You are suffering,' your voice is portentous, 'from the disorder for which you were prescribed benzodiazepines.'

This diagnostic cliche is your carefully considered diagnosis! And you are the head of a significant unit in a significant hospital.

You cannot help following the orthodox model, being adept in the brain, not its manifestations. Your discipline obliges you to think in disorders. Nevertheless, you know that my particular disorder was good days and bad days - it was written on a comer of my envelope. Now I am complaining about that - and more. I resent the fact that you are refusing to help me as much as I respect the modesty and sincerity with which you murmur 'It is beyond my competence. I am not an analyst.' I feel pain when you speak respectfully of analysts because you have a better interviewing technique than any analyst I have ever met, better than most psychiatrists, better than most doctors. Your gentle rationality is restful and healing in itself. All you would have to do would be talk with me exactly as you did before. Be the benign presence in the safe place. I can do the analysis myself. But, more than analysis, I

need information - you could share your special neurological knowledge with me. I am quite intelligent enough to carry it.

'Withdrawal only lasts a fortnight,' you say apologetically, as if discharging the unfortunate duty of telling me that the dog shit on my shoe is dirtying your carpet.

I am compelled to argue this one. Not a fortnight for me! Not for anyone else in the TRANX group! Not for Chris Holt! Not in the literature! I refer to the conflicting reports, the changes in findings over a twenty-year period, the influence of drug-company funding on research and, mordantly, I suggest you use Occam's razor to decide the matter.

'I know something about Occam's razor,' my own galgen humor stirs - 'I've been sitting on it for five years!'

'Well,' you murmur diffidently, 'it's like choosing which football team to barrack for.'

For a wonderful minute, my spine straightens. I feel six foot tall, robed in white, girdled in green, haloed in purple sparks. You are talking about our lives! Our pain! I don't know how people choose football teams if, indeed, they are chosen. I do know that this is not a fair response to Occam. Then I fall into a torpor from the difficulty of containing my grief, disappointment and righteous rage.

But there is no point in arguing. Clever and lovable as kelpies are, they are not renowned for independent thought. In due course, the Royal College of Kelpies will succumb to the unanimity of recent findings (and the spectacular threat of the English legal proceedings). The College will set up a subcommittee, draft a few guidelines and then, too late to succour the present season of sufferers, or prevent the next several seasons, you will acknowledge that benzo withdrawal is prolonged beyond anything observed in other drug problems and uniquely painful, too.

I fixate on the shiny broken lock of your shiny black case. I slump, realising that I am only seconds away from complete dissociation.

Strenuously, I swing my eyes anywhere away from the shining. They fall on your right shoe. I force myself to examine it critically. Plain, nicely polished. You are not wearing your notorious socks - not on the right foot, anyway. Fletcher Jones strides. White coat. No

gratuitous genital display: we are not here fighting the battle of the sexes. You are not punishing me because your wife gives head resentfully or not at all. Perhaps you don't even have a wife; perhaps you're queer as a coot and live in the country with a catamite. The great, bitter furrows at the comers of your mouth betray a longstanding tension but you don't pass it on to me. Your upbringing and religious beliefs and sex preference are irrelevant to your vocation for medicine. You are a doctor and I am a patient. I will leave here with my dignity intact.

I realise that I haven't seen your eyes yet. I've looked towards them often but still haven't looked into them. I have to raise my head to raise my eyes. Yours are not yellow, like a proper Kelpie's, but a decent sweet-sherry brown.

I have to get through this somehow. Since you are not going to help me, I have no reason to concentrate on what you say. I drift in and out of the conversation like a minnow flirting with a soft drink can. I am beginning to feel sorry for myself and I say irascibly 'I suppose the people who most need it are the people who suffer most?' In all of your various voices, your diction has been beautifully clear and quietly modulated but so neutral that I cannot tell whether you are English or educated Australian. Suddenly I hear a startled burst of dreadful flat vowels. 'I wouldn't say that,' you return. 'I wouldn't say that.' 'South African?' I ask myself. But they have gone before I can decide.

Most of my life seems to have been spent at the end of an infinitely elastic tether. I was at the end of it when I made our first appointment. And I am at the end of it again. I ask you to refer me on 'as a matter of urgency.' Promising to send me a referral, you write an unequivocal note to yourself in your wonderful clear hand.

I maintain my self-control while I return the flagged file to my lawyer. Then my eyes float on tears. There is an obvious haven in the City Centre for any survivor of iatrogenic rape. I reach Healthsharing Women just as my eyes start to splash down my cheeks. This is a practical establishment; it has no Buddhist commitment to tranquillity. In fact, it is as busy and productive as most of the women's facilities. With modest government funding, Healthsharing Women does everything. Yet it is as tranquil as the State library used to be. I ask for a friend who works there. She is out, but the receptionist, seeing that I am in trouble, asks if I would like to see a counsellor. Yes ... Oh yes ... Please.

I am shown into a comfortable room where the charm of the sparse furniture compliments the airiness of the Victorian high ceiling. From the light on the Post Office roof, and its pillared dome, we could be in Dublin or even in Rome. It takes very little kindness to stabilise me and restore my will to resist.

But I haven't fully assimilated everything that happened with Dr. Blank. I am enraged at his refusal to distinguish between benzodiazepine, symptoms and prior illness or to focus on the exact nature of the prior illness. I am resentful and disappointed in his belief that he can't help me. But these stresses are trivial. The trauma that makes me haemorrhage conflict and indecision is this: he is referring me to Professor Guppy, the man penultimately responsible for my receiving Ativan instead of lithium!

#### CHAPTER 9 AN APPLE A DAY

Primum non nocere.

Hippocrates

#### **HEALTH AND ILLTH**

We shall understand the pattern of destructive medicine more easily if we consider modem doctors as epigones of their classical heritage.

An individual called Hippocrates, who was born on the island of Cos near the western coast of Asia Minor around 460BC, gave his name to a collection of writings that reflect the teachings of the Coan school of medicine. Coans practised a holistic tradition that rejected the religious bases of treatment by necromancy and invocation in favour of observing natural processes and re-establishing the body's harmony both internally and in relation to its environment. These doctors followed procedures that had a rational foundation but also stressed the importance of ethical principles.

Cnidian medicine, practised on the peninsula of Cnidus, adjacent to Cos, was much closer to our own prevailing model: where the Coan tradition focussed on the patient living in the real world, the Cnidian focussed on the disease residing in the patient, seeking to find cures for diseases rather than health for people.

The Coans were concerned with health and the Cnidians only with Illith. Modem doctors preach Hippocrates but their practise is Cnidian.

The festering conflict over how to deal with the AIDS crisis is a clear example of the conflict between Cnidian and Coan. This epidemic is entrenched. This disease is lethal. There is no cure in sight. The most optimistic guess for the discovery of a cure - not just a palliative - is that it might be ten years away. Or ten decades. While people are dying, technologically oriented latter-day Cnidians demand more money to search for cures, refusing to share responsibility or pool resources with Coans and health educators even though the real and present danger of AIDS means that we cannot afford to wait for cures that are nowhere in sight.

Only the Coans, who draw their philosophy from the community medicine movement as well as from the gay movement, can save the healthy from AIDS. In addition to slowing the spread of the disease from the sick to the well, they can also give support and guidance about lifestyle that slows the progress of the disease in people who already have it. Australia's success in containing the epidemic, even though we have one of the world's highest per capita rates of infection, puts us in the forefront of AIDS control. The process is not yet complete, but it is a success - essentially a success of Coan medicine.

The conflict of Coan and Cnidian is nothing new where incurable diseases with a strong psychosocial component are concerned. The VD statistics of the period between the Great War and the American involvement in Vietnam demonstrate very clearly that syphilis and gonorrhoea could be effectively controlled, although not eliminated, by educational and hygienic means well before the discovery of penicillin. Penicillin merely supplied a cure that relieved the community of the inconvenience and embarrassment of prevention. If resistant strains emerge, use more penicillin!

Magic bullets are more glamorous than soap and water, king hits more macho than the homely condom, and silence is more comfortable than ascerbic messages that kiddies may read in railway toilets and discuss at the dinner table.

Ideally, Cnidian curative penicillin would have been used to mop up those infections that escaped the Coan preventive barriers. Instead, cure replaced prevention because, although cure is more expensive, it is less morally and socially demanding. Coans can accept Cnidian methods where they are useful but Cnidians refuse even to consider that Coan methods may work.

Epidemiology shows that, well before scientific intervention affects the incidence of infectious diseases, they decline because they have reached an ecological balance with their hosts. Most of us will be familiar with the ten-year saga of myxomatosis and rabbits that left us with a reduced population of rabbits that are myxo-resistant but with a better understanding of the ecology between host and disease.

Improved sanitation, more abundant and varied food, less overcrowded shelter and more careful hygiene accelerate ecological balancing in humans while quarantine contains epidemics. The nineteenth century *cordon sanitaire* that limited the spread of cholera

and plague in Europe, America and those parts of the world where quarantine could be imposed, reflected a Coan approach.

Deaths from tuberculosis almost halved in New York between 1812 and 1882 when Koch first isolated the bacillus. Deaths were more than halved by 1912 when the first sanatorium was opened and dropped still further by the time antibiotics became routine. That is, over about one hundred and forty years, evolution and Coan social intervention reduced the death rate from 700 to 48 per 10,000 people before Cnidian science found a cure.<sup>2</sup> Only a small minority benefited from streptomycin: the vast majority were saved by evolutionary and social change.

This pattern occurred for most of the infectious diseases in industrialised countries. Trends in morbidity and mortality over three centuries show that improvements occurring in advance of ecological balancing are not related to medicine but to nutrition, living standards and personal behaviours such as reproduction and smoking.<sup>3</sup> When the BCG vaccine arrived to fanfares, the pandemic of TB that had emerged with the Industrial Revolution was already waning.

Despite such copious evidence from medical history, a disproportionate amount of money and energy is spent on Cnidian medicine that cannot possibly be justified in dollar cost-benefit terms and certainly not in relief of suffering. Cnidians often argue that they are forced to undertake reactive medicine because patients, the community or the government do not appreciate pro-active or preventive measures. Yet the general public seems to understand the issues well enough to prefer prevention over cure.

Cnidian technological medicine reflects the interests of the medical industrial complex. Holistic Coan treatment looks to the needs of the patient. Regrettably, Cnidian medicine appeals to government through entrepreneurial lobbying and government is impressed because it seems more hard-nosed than Coan. Diana Dutton analyses this paradox:

The government responds to soaring health care costs by cutting back on preventive and primary care services known to be highly cost-efficient; at the same time, private industries expanding role in both basic research and health care delivery is taking a new slice of profits from the shrinking biomedical pie. Unchecked, these trends will squander resources on the rich while constricting basic services for the poor. Why, in medicine, long considered the most humane of professions, is this happening?<sup>4</sup>

Obviously, there can be no single explanation for such a complex development but one fact is worth noting: the redistribution of wealth through the taxation system is considered socialist and thus undesirable only if the tax dollar goes to the poor. Using taxes to subsidise research into products or services that are then marketed for profit by private enterprise is considered socially responsible.

Cnidians do not see nationalised health insurance or alleviating poverty, once known as the 'mother of disease', as medically justifiable but they see nothing inappropriate in using tax dollars to fund IVF, organ transplants and other high-tech procedures that create jobs and wealth in the medical-industrial complex.

Research from Britain, Australia and the United States shows that poverty causes ill health. We are all, no doubt, familiar with those gloomy maps that come out every time there is a health survey showing that high death rates occur in poor suburbs and sometimes more precise breakdowns of particular causes of death. Poverty increases the risk of low-birth-weight babies, higher perinatal mortality and cot death, obesity, and all the major diseases leading to death.

Housing is a crucial factor in poverty and ill-health. Rates of homelessness, poor housing, state housing, private tenancy and own-your-own correlate with health. Rates of gastroenteritis and dysentery, meningitis, tuberculosis, upper respiratory infections, asthma, anxiety, depression and other psychiatric illness, accidents, hypothermia, increased exposure to radon, asbestos, lead and other pollutants, increased risk of alcoholism, violence, and vandalism are all known correlates of poor housing. Sometimes the correlation can be made cruelly specific: private tenants have greater stillbirth and infant mortality rates than owner-occupiers.<sup>5</sup>

For every story one hears of a doctor who will testify that a family must get public housing because damp and mould are exacerbating chest trouble, one hears of a dozen who prescribe BZD. More seriously, the medical-industrial complex competes with housing and other preventive measures for the tax dollar.

Sylvia Ann Hewlett analyses the cost-benefits for the USA of neonatal intensive care compared with the cost of preventive care for pregnant women and women not yet pregnant. In 1989, the cost for caring for dangerously premature babies was \$2.4 billion annually with a lifetime average cost per child of \$389,800 compared with \$400 to \$1,000 required for antenatal care.<sup>6</sup>

The Cnidian attitude towards tax spending produces some curious anomalies. Influenza is twice as common among poor adults as among affluent ones and influenza death rates are 50 per cent higher among

minorities, due to the depressant effects of malnutrition, bad housing, pollutants and stressors on the immune systems of people living below the poverty line. Yet preventive care - such as flu shots - is usually less in at-risk groups.<sup>7</sup> Improved food and housing is not seen as part of preventive care although improving conditions can be a better investment even than immunisation programmes. An American study of children's hospitalisation for measles and whooping cough showed that infections related more to the economic circumstances of the family than to whether or not the child had been vaccinated.<sup>8</sup>

Then there was the study of the use of genetically produced human growth hormone to treat short children. It ignored nutrition - which is, alongside heredity, one of the two most significant variables in growth and the most important influence on growth as either cause or cure.<sup>9</sup>

'We seem condemned,' says Diana Dutton, 'to triumphs of biological wizardry and failures of social management.<sup>10</sup>

It is difficult to understand the strength of ideological bias in government preference for Cnidian over Coan medicine when one considers the excellent cost-benefits of preventive care spending. On American figures, \$1 spent on nutrition and care of a pregnant woman saves \$2-\$11 on other services. Prenatal care for a pregnant woman for nine months is \$600 while medical care for a premature baby for one day adds up to \$2,500. A measles shot costs \$6 as against \$5,000 for the hospitalisation of a child with measles. To treat a pregnant woman addicted to illicit drugs for nine months costs \$5,000 but to care for her drug-exposed baby for twenty days will cost \$30,000. School-based sex education for one pupil for one year costs \$135 but twenty years' welfare support for a teenaged parent's child would be no less than \$50,000. Nevertheless, in the late 1980s, Australia spent less than 1c. of its health dollar on prevention of illness and the development of health promotion strategies.

When Cnidians announce that they are getting better at in-vitro fertilisation, they see no incongruity in announcing that they still know very little about why the sperm count has been declining steadily in males of the industrialised countries since at least the 1920s or the nature of the connection between frigidity, spastic tubes, and infertility in women. It would cost about \$75 Australian per woman to provide education in sexual hygiene to prevent pelvic inflammatory disease one of the main - causes of blocked fallopians - saving about \$45,000AU per healthy IVF baby on 1987 costs. A premature infant

requiring neonatal intensive care may cost as much as \$15,000AU per day for up to five months.

It is difficult to get out a cost-benefit on IVF because so many of the costs cannot be measured in dollars. How many husbands, confronted with the emotional and psychological burden of multiple births, shoot through? What is the value of an ovary removed because ovarian cysts developed following stimulation by Clomid/clomiphene citrate?

The cost of a heart transplant is around \$75,000AU, and the cost of immunosuppressant drugs is around \$12,000AU per annum. In 1990, Australia's total transplants cost eight million dollars and immunosuppressant drugs cost two million. Has anyone budgeted on the lifetime cost of successful organ transplants relative to disease prevention?

In the olden days, refusing to spend a very little money on prevention because it is socialistic or the beneficiaries are undeserving and then spending a very great deal of money on cure would have been called penny-wise and pound-foolish. It was not considered a sensible way of going about things.

The Cnidian/Coan antinomy is not just between doctors who have a social conscience and those who do not but between those who respect the value of preventive medicine and those who focus only on cure. Thus, the orthopaedic surgeons who went public on seat belt legislation and the anti-smoking doctors who are helping to dismantle the tobacco culture, which has existed in the west for nearly four centuries, are Coans to the extent that they value prevention over cure.

But the connections between seat belts and road trauma or smoking and cancer or heart disease are more visible and more direct than other problems such as child abuse and iatragenic drug addiction in which the medical pathology is only one component in a total health environment.

Dr. Dora Bialestock had to overcome immense resistance among Victorian doctors when she tried to publicise the battered baby syndrome in the late 1950s and early 1960s. That problem is still unsolved. Many, possibly most, of the doctors who are easing off the prescription of benzodiazepines continue to use the Cnidian model and simply replace them with other drugs.

# **PATIENT, HEAL THYSELF!**

I have been a consumer of health services since I was too small to stand on a lavatory seat to pull the chain. The benzodiazepine trauma revealed me to myself as a damaged survivor of Cnidian medicine and, reflecting on my medical history in the context of that discovery, I find that I have been wrestling with Cnidian medicine all my life.

I was not, indeed, poor - but I was a candidate for preventive care that was denied me in the crucial years so that my conditions degenerated. One of my minor treats on visits to the mega-hospital is to watch a new consultant scan my history and remark delightedly that, over twenty-five years, my condition has not deteriorated according to expectation as I have aged. When I attribute this to life-style, most are unmoved and some are miffed. I do not rule out their services as a factor - but all the other patients in the clinic are getting the same services. The only factors that make me special are life-style ones.

As I write, I have a vivid picture of my solid lump of a baby, his face puckered with grief and his whole naked body red with rage, clenching his sturdy fists and yowling while he was forcibly stretched out and measured on a cold sheet of plastic. I had anticipated that the baby health centre would help me grow him up. They weighed him and measured him religiously, performed a PKU test at the appropriate time, and vaccinated him. But I suspected that the real function of the service was to collect weight and length statistics - as the covert function of the Royal Melbourne Show is to provide attendance statistics.

For a long time - from perhaps 1966 to 1976 - I was disappointed that the thoracic clinic was not helping me to get well, or even to get better. Then I realised that its true function was to measure my deterioration. I do not say that the chest bods were totally indifferent to my welfare, but that their intransigent refusal to consider environmental and emotional factors, their Cnidian emphasis on illth and neglect of health, meant that they set their goals very low.

The Cnidian habit of testing mechanical processes - the expansion of my chest, the flexion of my spine - independently of the person who owned the chest and the spine left me with a sense of failure when I could not do what was wanted. I often asked myself why I was being tested: competitively, to see if I could reach a standard? In which case, I was a failure. Or diagnostically, to find out something about me? I

was still asking myself this in my late twenties when I really knew the answer.

The lack of sympathy, kindness and I - thou communication aggravated my guilt over my apparently defective willpower and moral strength. I always felt that I was malingering because I could not measure up. The test equipment became ever more elaborate but the stem attitudes and hectoring approaches did not change. During my teens, the physiotherapist had a large chrome drum suspended over a cylinder by thin chains that raised it vertically along a gauge as I blew. The mega-hospital I attended in my university days had a small horizontal unit with a vacuum cleaner tube and fine graph paper. I have even been tested with a chestful of radioactive isotopes. In the absence of a human touch, they are all demoralising.

My peak flow measure increased one hundred per cent when a physiotherapist told me that it is technically impossible to breathe in. Since one only has voluntary control over breathing out, the trick is to breathe out as far as possible and let the atmosphere fill the vacuum created. In other words, the yogic principle of letting the lungs fill themselves. Yet the wallahs at the mega-hospital persist in hectoring patients to breathe IN! IN!

The exercise of the muscular-skeletal system called 'physiotherapy' is usually practised as a Cnidian procedure, treating the body as a structure of rods and levers, ignoring both the environment of the *milieu interieur* and the external world.

Practitioners whose warmth and sensitivity equals their stamina can make it work. I have a happy memory of the physios at the Sir Charles Gairdner Hospital in Perth, who worked me very hard without ever creating an atmosphere of competition and judgement.

One of the most exhausting features of bronchiectasis is the unproductive cough but these vigorous women never asked me to cough unless they gauged the phlegm was ready to come away. I used to leave their sessions feeling as exhausted and euphoric as if I'd been to aerobics.

The lungs lend themselves to construction in mechanical terms: they can easily be seen as areas of high and low pressure that work like bellows or sponges. But lung function is biochemical before it is mechanical: the bronchi expand and the blood vessels dilate under the stimulus of chemical messengers in the blood carrying fight and flight

messages from the old brain in response to environmental cues perceived by the cortex.

I once developed an asthma attack when a man who bad been instrumental in getting me unfairly sacked walked into a friend's party I did not recognise precisely who be was at the time but Gary, who is a Coan doctor, said that it took about forty seconds before I was puce and choking.

The Cnidian attempt to treat the lungs as bellows was often bizarre as well as cruel. At a time when my asthma was so bad that I was taking baths instead of showers and sitting down to dry myself and dress, a consultant in charge of physical medicine at the mega-hospital instructed me to breathe through a short small-bore tube - the barrel of a biro - and to run on the spot for X minutes to loosen the mucus in my chest.

The Cnidians also treat the lungs like a bottle that should respond to gravity. Thus, when the normal moisture collects in the lungs because repeated infections have stripped the ciliated lining of the bronchi, it allows infection to breed in stagnant pockets. The good Cnidian believes that if he turns the patient upside down the sputum will drain to areas with intact cough reflexes and the patient will be able to spit it out. This only works if the various branches are wholesomely relaxed. If an asthma attack is in process or if the patient is under stress, and the lungs are constricted, or if they are slowed down by benzodiazepines, gravity will not work.

I have repeatedly tried to explain to Dr. Deaf of the mega-hospital that my arthritic joints are too painful for postural drainage because the stress of the position causes pain, the pain prevents me relaxing and my lungs tighten up against gravity. He does not hear.

During the nadir of my benzo experience, when I had no voluntary control over my coughing at all, a young resident doctor at the mega hospital went to the telephone to order a physiotherapy appointment. He came back shaking his head.

'This is scandalous!' he said with the beautiful candour I sometimes find among unspoiled RMOs. 'You're on the brink of pneumonia and we can't give you an appointment. There just aren't enough chest physios any more - physios are all going into sports medicine for the glamour.' I loved him for his youth, his openness and his moral sense.

The trend to holistic healing began to permeate physiotherapy well before I learned of the advance. I had driven one hundred and sixty miles for my eight-thirty appointment at the mega-hospital, collecting a fine and a demerit point for speeding on the way.

When I arrived, the clinic was empty and the laughing nurses told me that they had been thinking of going into the street and shanghaiing patients. I thought I would have a leisurely discussion with a consultant and inquire about physio because I had had a persistent infection that was tiring me out for writing at night and on the weekends.

The young hopeful, who sincerely wanted to get on well with his patients, turned up to his first clinic with a pipe stuck in his top pocket. We had an amiable, if rushed, encounter in which I said that I was interested in getting physio. Somehow this statement was lost in a discussion of this and that in which I discovered that the current fashion in chest physio was more dynamic and more Coan than the style I had been used to. Then, somehow, Dr. Young was not there.

When I arrived, he had been engaged in a rewarding discussion with the other consultants and he had gone back to it as soon as he politely could, not registering that my expression of interest was a polite, deferential and - why not say it? - feminine request for help and not a cue for him to display his qualifications.

On the doctors' side of the cubicles, I could hear familiar voices murmuring `. . . well, if it's asbestos' `. . . no doubt of exposure . . .' `. . . .he's chronic. . .'

'Hey fellas,' I thought. 'It's me in here! I'm chronic too!'

The poor sods: they were trained to manage diseases but people keep demanding their attention!

## CNIDIANS, COANS, AND CONTRACEPTION

I need not have had three abortions if the doctors who prescribed my contraceptives had been Coan. Early in my fertile years (1952-70), the effective use of contraception was bedevilled by a persistent habit - derived partly from marketing and partly from Cnidian medicine - of giving only the best-scenario success rates for contraceptive methods and patronising only the method the detailer recommended.

The difference between a laboratory trial or carefully supervised use by well-screened patients and the messiness of real life may be as much as 40 per cent - for the Billings or Yuk method. But even a .8 per cent failure in a hormonal method is a 100 per cent failure for the woman concerned. The Cnidian approach would be perfect if the sperms met the ovum in a test-tube of spermicide but it is not so good for warm horizontal humans.

The Coan approach to contraception is the cafeteria system where all methods are made equally available with their merits and demerits clearly on view. The doctor's responsibility would then be to assist the woman or the couple to choose one that satisfied their needs and preferences at that particular time in their lives.

Until recently, only dedicated clinics did this: most private practice doctors followed their own preferences, prejudices and profit - which is why so many women were dissatisfied with their contraception. The doctor who boasted to me in 1969, on the evidence of his detailer, that he had the largest IUD practice in town did not realise that he was advertising his own laziness.

Please note that I was using contraceptives on each of the three times I became pregnant. First I was fitted with a diaphragm by a dour doctor who seemed to see sex as an onerous chore that women undertook for the privilege of being married - not a privilege that she had ever undertaken. One of the things she failed to tell me was that all contraceptives have a failure rate.

Contraception is not a treatment for an ill - it is a preventive that must be seen in a social and psychological environment. Barbara and Gideon Seaman, who described the diaphragm and spermicide as 'the queen of contraceptives' weren't just insensitive to metaphor - they were insensitive to sex. These writers underplayed what the Masters and Johnson team actually photographed: the diaphragm does not merely fit 'more loosely' when the vaginal canal expands in a sexually excited woman. The uterus lifts up and out of the device.

The Seamans do acknowledge that failure is *possible* 'if the woman is *highly* excited' but it would be more correct to say failure is *likely* if the woman is normally excited since uterine elevation is a predictable part of the response cycle in women who are capable of having orgasm through coitus. The coitally orgasmic woman is protected only by her spermicide and her cycle.<sup>17</sup>

One could argue that the diaphragm is suitable only for inorgasmic women.

I had morning sickness with the first missed period and I was outraged to find that the disgusting flabby saucer and unnatural smelling, dripping gel had failed me. I cannot blame this conception entirely on the contraceptive method. I was cohabiting with the most carnal partner I have ever enjoyed and needed rigorous protection.

I detested the offensively inoffensive smell of the gel - which was also relatively expensive. So, as an undergraduate supporting a wastrel, and enjoying a splendidly athletic relationship, I was deliberately frugal with the repeat doses. I took ten months to become pregnant - less than one woman-year of use.

By the time it was diagnosed, I had left my partner because gourmet sex was not enough to compensate for his fecklessness and stupidity.

I procured a backyard abortion with enormous difficulty because my lungs were not bad enough to justify therapeutic (semi-legal) termination but were quite bad enough to make me an anaesthetic risk for doctors practising outside the law - which most of them did in 1961.

During my diaphragm days, Dr. Angel prescribed hormones for dysmenorrhoea. They were presented in the form of chocolate-coated pills so that the patient would not realise that they were not, in fact, just any pills, but The Pill. As soon as my next period came, I returned to the gynaecologist who had prescribed the chocolate-coated contraceptives and asked him to fit me with a Grafenberg ring. You see, he had not revealed the valuable side effects of his ineffectual treatment for dysmenorrhoea. That was not the end of his negligence.

He fitted the ring without an anaesthetic allegedly to save me, still a student, the expense of an anaesthetic and a morning in hospital (and to save him the inconvenience of traipsing to the nearest hospital?) To be fair, he did say that if I couldn't bear it, he would do me in hospital.

The fitting was very like the abortion: several different sorts of pain, sweating, prodding, and praise for my good behaviour. Afterwards I wondered if, as a Catholic, he did not feel justified in administering a tittle of punishment in advance of the crime - just to make sure that at least one of us paid for our sins.

He did not notice what a man of his eminence should have noticed that I had a bichrornate uterus and was unprotected in half of it. And in

three months, I was pregnant again. This time, I was aborted at great cost and distress in Collins Street.

My suave GP then fitted another Grafenberg while I was in hospital and unconscious but he also failed to notice my abnormality.

I went for a urine test at the first possible moment after the next missed period and had myself referred back to Collins Street, where I was promptly and efficiently aborted by a young doctor who gave me cut rates (£60 as opposed to £200) and a message for my GP: 'Tell him he is not responsible for the failure of the ring.'

He looked like a schoolboy who has just discovered a hole in the wall of the girls' dressing shed. For the first time, my cervix was sore after a dilatation. He had obviously had a good feel around - but he did not enlighten me.

By then, the chocolate had melted on the oral contraceptive and Dr. Suave prescribed that under its proper name, warning me that I might feel bloated and miserable but that there were other formulae on the market and we would keep trying until we found the right one for me. He also said not to worry if I got thrush, it was sometimes a side effect but easily controlled. This was pretty good advice for 1963!

A Coan doctor would have identified my pressing need not to get pregnant - different needs at different times of my life - and the limitations of each method: probably my best bet would have been to ask my partners to use condoms. Condoms never occurred to me at the time - in fact, I have never seen one in action. I was proud to be in charge of my own fertility - even though my actual control proved to be more illusory than real.

I turned out to be one of those women who become depressed on oral contraception. Since I needed an effective contraceptive so desperately, I did not want to believe that my blessing was also my bane. I was so burdened by growing up as an unwanted child and I had such trouble making my way in the world that I was always able to find some plausible psychological explanation for my depression and contraceptive research was so patchy that I could always criticise it enough to defend orals.

Although there was plenty of public controversy about the ill effects of The Pill, none of my many doctors - including the psychiatrists - ever queried whether my depression was related to the hormones I was taking. I was not convinced of the connection myself until I had my

tubes tied. I was euphoric - especially before bed when I cleaned my teeth or took my asthma tablets. For about a year, I felt as if I had laid down a heavy burden until, gradually, I began to suspect that this happiness was excessive or factitious. Finally I concluded that what I had interpreted as a psychological response to the absence of the pill routine was really a physiological recovery from the depressant effects of the pill itself.

It was a preview of what would happen with Ativan: the presence of diffuse psychological explanations for distress covered the more simple and correct pharmacological reason. Doctors are not trained to use Occam's razor and the lessons the patient learns in the school of hard knocks are slow and uneven.

#### **WORKING MOTHERS**

My father believed, possibly as a projection of his own ambivalence towards me, that I could not survive childbirth and told my first husband so. Certainly, I was apprehensive about this myself. So when I became clucky, I went to one of my early thoracic doctors to ask about pregnancy. He must have been a Cnidian - a Coan would never have made the mistake of saying I was healthy enough to bear a child without asking how I would *rear* one.

I was not in a position to act on his advice for several years but when I did, I experienced such terrible asthma during pregnancy that I could not see how the foetus would not suffer with me. My bronchiectasis worsened afterwards and the early promises of arthritis were fulfilled.

A Coan would have realised that my lungs and back would need as much care as my belly and made sure that I had someone to help me with drainage before and breathing during and after labour. A Coan would not have drawn a demarcation line at the navel and ignored my lungs.

About two years after the birth, when I was in status asthmaticus, I had to give my history to a new resident at the mega-hospital.

'Oh you are in a bad way!' he said. 'But never mind - just think how much worse it would be if you were a man and had to work!'

In fact I was already working. He should have known better. In 1967, the economy of the affluent society depended on drawing married women, including those with young children, into the paid worldforce. The doctor could hardly have known the workforce statistics - but he might have read my medical history.

When will they ever learn? About ten years later, I developed the condition that I called The Horrors. TM continued to work for sleep and for relaxation on good days but was ineffectual on bad days. My GP prescribed first Stemetil and then amitriptyline and Valium without the slightest effect.

I muddled along with these various attempts at a chemical solution to the problem and then decided to look for a psychiatrist who knew something about the biochemical basis of what I had not yet learned to call mood-swing. Dr. Cabernet suggested someone from his own year.

Public transport workers were holding a stop-work meeting on the day of my first appointment. I arrived at the upstairs-front terrace room late, to find the doctor sitting with his back to the windows but still visibly wearing a hand-finished suit, probable Gucci shoes and a suspected Pucci tie. He did not try to control his annoyance.

'I am sorry. I reached the City in good time but the traffic took an awfully long time to clear after the stopwork. I found myself sitting on a bus that couldn't move for banked up cars and I couldn't decide whether it was more risky to leave the bus to find a phone or to stay with it and not call you.'

'You've had all day to get here!'

I trust you will not fail to note that the doctor assumed that I had nothing more pressing to do with my time than anticipate my consultation with him. And this was 1977, by which time thoughtful people could not fail to recognise that the affluent society required married women to join the workforce. There was a better than fifty-fifty chance that any female patient attending Dr. Gucci would have come from paid work.

'Well, no ... not quite. I spent the morning typing a review I wrote last night, then I got the last tram out to give a lecture on natural childbirth to a mothers' club and when I got back into the City, I delivered the review to the *Age*. I made perfect time all day until the last hour.'

Having apologised earnestly for my tardiness, and shown that it was not irresponsible, I had a slight hope that he might unbend or even apologise for his surliness - say 'It's been a hectic week' or 'It gets quite nerve-racking waiting for patients who don't ring.' Any little sign of humanity could not fail to win my trust. But he was not mollified and I was not won. We did not part friends.

Most of the doctors I met at the mega-hospital shared this Cnidian blindness to social context. It was as if they did not acknowledge the world outside the hospital or, indeed, time outside our appointment. What they could not see, did not exist.

#### THE MUSHROOM TREATMENT

I took years to recognise why my conversations with the consultants were so unsatisfying. We often had long and informative discussions about academic matters. They certainly did not try to quell my interest in various processes. They explained in great detail the difference between an analgesic and an anti-inflammatory. But they were very light on practical guidance.

I tried to get guidelines as to when I should use antibiotics. Two consultants and a resident willingly told me that sputum colour and density was no guide because someone had discovered that phlegm could look virulent but not contain infective organisms.

They did not, however, answer my question - although I am sure they believed they had. It was not an academic question but a practical one. So I decided to use antibiotics if I were breathless and also had heavy sputum. It took me years to discover that by the time I was breathless it was too late.

Then there was the time when I was deep into benzo exhaustion and also carrying a persistent, heavy chest infection. I began to wonder about old-fashioned bedrest. But Dr. Scratch duck-shoved. 'On the one hand,' he said. 'And on the other. . .'

The most intractable medical silence I had to endure has been over air pollution. I had never, in thirty-six years' attendance at the megahospital, managed to invite, persuade, trick, cajole, seduce, torment, incite, or provoke a consultant to discuss it.

When I announced 'I'm alright except when there's photochemical smog' or 'I'm very weary because of the pollution', I would be met with magisterial silence. Nothing. Not anything. Not a thing. Not a sausage. Sometimes I thought I was mad. Sometimes I thought they were responding irresponsibly and maladaptively to a situation that they could not control.

Then, one inverted day, my routine elicited a response. `. . all right except ... smog ... weary ... pollution.' The young consultant brightened and set me to rights. 'Asthma has nothing to do with pollution. Hospital admissions and deaths do not go up on days of high pollution.' This illustrates two points about the Cnidian approach. Commonsense, informed observation and personal experience count for nothing; only statistics count. And Cnidians are not fazed by any degree of unquantifiable suffering among their patients but they do not like death. It is so obviously a defeat of their skills. What's more, it involves paperwork.

This is one reason why the benzodiazepine scandal has taken so long to boil over - there are too few corpses. As Professor Dukes says 'If people are not dying left and right from a drug it's very easy to talk the problem out of existence for an awfully long time and particularly when the drug is making money.'19

Visible suffering counts for nothing without tests to prove that the patient is ill. I have had two encounters with pseudomonas. Like golden staph, it is one of the germs that thrive in the aseptic environment of hospitals; I believe it quite likes to live on antiseptic soap. I was feeling depressingly ill and the routine antibiotics had not fixed me so the consultant ordered a sputum culture. It showed either nothing or nothing that the routine antibiotics could not cure (but hadn't). I dragged on for almost a year-feeling really like an invalid, knowing that a sunny day would improve my spirits but not my lungs. A second culture was also negative.

So I went to a private pathology service. My first telephone call was like getting through to Florey. 'We seem to have something but it's a slow grower. Ring back on Monday.' The mega-hospital had not allowed for slow growers. I was excessively tactful when I took the results to the clinic.

This was in the years before Dr. Cabemet's complexion had begun to show signs of age and high living: he could still blush. He offered me the choice of ten days in hospital or daily attendance for large shots of tetracycline. (I can't remember any details of the second infection perhaps the mega-hospital had stopped rushing its cultures.)

The same indifference to illness in the absence of positive tests prolonged my benzo suffering: as test after test proved negative, the doctors simply said 'nix'. None of them bothered to say 'This test may be negative but the patient's definitely sick. What else can we try? What can I do to help her?' Only one of them called me hypochondriac to my face. Rule one hundred and one: if it doesn't show up on a test, you are not sick. Goodness knows how AIDS was ever discovered.

The scan ordered by Dr. Manners certainly revealed nothing but neither did it console me. I knew that my memory had become unreliable in several ways, and that some intellectual processes were not right. Two years later, enraged at my failure to return to normal, I chased up a psychologist who worked at a hospital where Valium was handed out to the patients in bags of five hundred. A small battery of psychological tests showed that results of a test for short-term memory for random detail and a complex maze-running task were significantly below my other scores although still not below average.

The high tech scan said I was normal but the pen-and-paper tests showed otherwise. Almost all BZD survivors have done the rounds of the consultants and some have had neurological run-downs but I have never heard of one who was investigated by a psychologist using those tests that are sensitive to benzodiazepine addiction and withdrawal.<sup>20</sup>

Before any hospital embarks on magnetic resonance imaging (MRI), management should ask whether the increased information from this development of the CAT scan will really encourage better diagnosis and treatment. On 1990 figures, MRI costs between three and four million to install with recurrent funding of about one million annually. Each procedure costs roughly six hundred dollars. Will MRI miss damage that can be picked up by \$250 worth of psychological testing with neither capital investment nor recurring costs?

Coans think in systems - and by this I do not mean groups of organs like the cardiovascular system that contribute to a total process. I mean the interaction of many factors that feed back into each other - like earning a living, money, housing, cigarettes, smog, climate, the emotions, the stress response, the immune system, the hormones and the lungs. Cnidians think in terms of manipulating single pairs of variables, even though this procedure is only feasible in the laboratory and hardly feasible at all in real life.

A Coan would have been able to examine my contraceptive depression and perhaps even my asthma as systems phenomena and not merely to concentrate on my psychological or somatic conditions in isolation from each other. A Coan would realise that I have a conflict between maintaining my skeleton and maintaining my lungs. A Coan might not have picked up BZD sickness but at least s/he would not have assumed that I was well simply because tests showed nothing.

During those magical days of the 1988 Melbourne tram strike, when the unions left trams across key city intersections to block traffic and welded bars across the tracks to prevent management shifting the trams, I walked nine city blocks at a brisk trot, morning and night, for six weeks. Sometimes, I walked down the middle of Elizabeth Street where the silent green avenue stretched, it seemed, to the Haymarket roundabout. Before the trams were moving again, I had a heightened sense of well-being such as I rarely enjoy. And this was in the middle of benzo withdrawal! Exercise is a more biologically appropriate and effective response to anxiety than pills and is also effective for some stages of withdrawal.

But the tonic effect was not just on my spirits: I felt altogether healthier - except for my right hip and knee, which were almost painful enough to make me think about going to the doctor. The exercise that was good for me was bad for those joints.

Dr. Deaf would never acknowledge the conflict of lungs and bones. Lungs were his territory but bones did not count - they were not his territory. I dreaded the point in our consultation when he would recommend drainage and I would explain (again) and he would refuse to hear (again). He was so persistently and stupidly unresponsive that he reminded me of an episode during my transcendent labour.

I had had an inexplicable diarrhoea at about ten o'clock and begun to wonder if claret and papaya really do mix. Then, as I was leaving the bathroom, I was overcome by a powerful resentment of my foetal passenger and the urge to push. The words that formed in my head were 'I'm going to push you out!' I returned to the toilet and pushed. The mucous plug slipped out effortlessly and lay glistening like a beryl in the white bowl. When I arrived at the maternity hospital, the waters were draining rapidly away but no one treated my condition as urgent.

I was submitted to an enema for my already empty bowel, shaved, and told to go to sleep (like a good girl) and the (nice) doctor would come in the morning. I was quite ready for sleep and settled down on a

bed in an anteroom of a delivery room. But sleep did not come. I found myself humming I 'yo ho, heave - PUSH!' to the tune of the 'Volga Boatman' and spitting between times into a hospital mug. After a while, I began to regret my lost sleep and to ponder my situation. It then struck me that I was in labour! I was alone!

What would happen when the baby came? I could not ring for help because the bell was on the other side of the room. I could not get out of the high bed because the brake was not on its wheels and I dreaded slipping as it moved. I tried to punt myself across the room by clutching at door lintels but struck a patch of wall with no hand-holds. So I yelled. And the words that came were 'You won't let me get to SLEEP!' I was embarrassed as soon as they were out - fancy screeching at an inoffensive perinate - but the words did bring a nurse who peered between my legs and said 'Oh God! It's crowned!'

She sent for the doctor and I was whizzed into delivery. By this time, my mug was almost full of white froth.

The doctor did eventually come and went through the pretence of delivering a baby that was nearly there. It was all very cosy with one doctor, one midwife, and, I think, two other nurses, but I was parched with all the coughing and pleaded for a cup of tea. I did not even get an ice-chip or a wet flannel to suck. So I shut up and concentrated on the delicious work of having a baby.

Apparently, the orthodoxy then was that birthing women need to have their chins on their chests to push and I had one nurse designated to shove my head down. Now, I cannot breathe properly when I'm hunched over so I persistently lifted my head to fill my lungs before the next shove/push. By then, there was no way I could have expressed my distress in words. I could not turn my head to bite the pest or even swivel my eyes sideways to fix her with a basilisk stare. My will was completely disengaged from my body. So I changed my rhythm to incorporate this interference: 'yo ho, dodge-shove - PUSH!'

We must have kept this up for over two hours, without the nurse ever realising that I was not being stupid or mischievous - I needed air and air I was going to have!

Dr. Deaf's monotonous attempts to force me to hang upside down were just like the nurse trying to force my head down. Cnidians not only do not listen to patients, they do not observe them either.

A Coan would have identified the interaction of my various problems and also the points at which my attempts to achieve health were undermined by self-destructive decisions that aggravated my illth.

I had learned to hold my stepmother's warnings in contempt: a cut between the finger and the thumb did not cause lockjaw, washing my hair during my periods did not drive me mad, people did not inevitably die if they have three strokes.

One of the most traumatic experiences of my childish life was looking at my bloated reflection in the bowl of a primary school drinking fountain and realising that I had drunk water after eating fruit. I spent the afternoon in horror at my desk, waiting to be stricken by excruciating pains. Reflecting on their failure to strike, I decided that the grown-ups were terrible alarmists. The first time I walked through rain without an umbrella and didn't get my death, I felt triumphant.

When I left home to live in University Women's College, I was so bubbling over with suppressed energy and initiatives that I really could not imagine what my limitations might be until I had passed them. This usually meant that my recklessness was reined in by a chest infection or a severe asthma attack.

A Coan might have reduced the margin of error in my trial and error regimen, for example by questioning my decision to be a working mother. With my degree of bronchiectasis and asthma, and my potential for arthritis, I could have been a successful mother or a successful working woman but not both.

I have met very few doctors who think in systems: remembering what the effect of my hormonal cycles had on chest infections, I asked a chest doctor how climacteric was likely to affect me. He giggled nervously and told me I'd be safe with antibiotics. Plainly he had never considered such a question and found it embarrassing - yet bronchiectasis is a disease that degenerates over time and lung function, like bowel function, responds to the female hormonal cycle.

Roughly speaking, consultants are highly likely and general practitioners are quite likely to be Cnidian - except for those GPs in community health services, the occasional trade union service and the women's health clinics, who are likely to be Coan. Although hospices, and hospitals that offer alternative birthing services, are probably Coan, most hospitals are likely to be run according to the Cnidian rule. Doctors who invoke the sanctity of the doctor-patient relationship to

avoid auditing and who resist national health insurance on principle, do nothing to ensure continuity of service in the mega-hospital.

Dr. Scratch is an irascible little man - so unpleasant that I was forced to employ the Duchess of Windsor technique for my own peace of mind.

It is a form of ego massage, easily adapted to the doctor-patient relationship. The patient - usually a woman - leaves her personality and interests in the umbrella stand, concentrating her entire attention on the doctor - usually a man. She encourages him to talk about himself, rapidly finding out what his hobbies, interests, anxieties and ambitions are. He will be so charmed that he forgets to be unpleasant. This worked so well with Dr. Scratch that we had quite civilised encounters for several years.

The only times I did not see him was when he was on holiday or at conferences. I assumed that the mega-hospital had begun to assign patients to the same doctor to ensure continuity of service. When my addiction was becoming intolerable, I found that ego massage became impossibly difficult. I tactfully inquired whether I might change doctors only to discover that there was no system and thus no possibility of change. Dr. Scratch had simply been choosing my file from the heap whenever it appeared there. Since the Cnidians are treating conditions and organs, it does not really matter which doctor gets which patient unless the doctor is dependent on the patient.

## **STATUS ASTHMATICUS**

In 1966, when my son was a toddler, I was admitted to the megahospital in status asthmaticus and with a severe lung infection. When the late Dr. Brian Marks noticed that for several weeks I had been complaining in the outpatient clinic of feeling poorly, he instructed one of his juniors to admit me as an in-patient. I had been taking one capsule of ampicillin - then a new and still expensive trial drug - every six hours. When Dr. Marks ordered the junior to increase my dose to five capsules six-hourly, and the young man demurred, Dr. Marks said 'Look at her sputum!' Which was indeed unlovely -dense, green, foul and copious - not high tech at all. I only saw Dr. Marks a couple of times and have no clear picture of him - I remember him as a rather slight man, unremarkable except that he recognised that I was ill and acted decisively.

I spent a week in hospital, having massive doses of ampicillin and four hourly (or was it six?) injections of bronchephron. These Cnidian interventions cured the infection and broke the asthma attack - until next time. My stay became participant-observation of Cnidian medicine although I did not discover the actual term until twenty-five years later.

The first drama happened when I was being admitted to inpatients. Resuscitation was all the rage at the time. Suddenly the resident who had been taking my details said 'cardiac arrest'. The low, delighted cry was taken up by all the white-coated students who flocked around a trolley carrying an elderly man in Sandy Stone pajamas who had come in from the ambulance entrance. I could see very little from my wheelchair except white backs and stethoscopes bouncing like Saint-Loup's monocle so I was left imagining the wonders of modem medicine until a nurse rescued me.

There was a survivor of this brave new procedure in the women's ward. She was a 22-year-old unmarried mother of two toddlers, each by a different father, and her heart had stopped during an asthma attack. With the great kindness and tact of women, the other patients tried to conceal this last fact from me.

She reminded me very much of the dustman's wife and daughters who had once rented a house from Uncle Dave. The girls were pretty enough but the mother was a nasty warning of what would come to them with repeated pregnancy and poor food: Mrs. Dust was scrawny, toothless, grubby, unkempt and beaten.

Of course, our young revenant had been washed and brushed but she was scrawny, motionless and mute in her wheelchair – Mrs. Dust before her time.

'The OT has taught her cotton-reel knitting and we think we may get her to talk again!' burbled the resident.

Her brain had been without oxygen so long that she had returned like the victim of a severe stroke. I never saw her pick up the cotton-reel that lay in the folds of her rug. I never saw her eyes follow any activity in the ward or respond to any of the people who attended to her so dutifully. Her children went into care because she had no relatives and the fathers had shot through. She would spend the rest of her life in care too.

Another young mother had come in for a routine biopsy and had bled rather a lot. She was hooked up to a drip in the bay behind my bed. An 83-year-old suffering from dementia and pneumonia was brought in by her two daughters who felt they could no longer nurse her. She protested loudly and vigorously at their dereliction, demanding fresh batteries for her transistor radio and an immediate return home.

She went wandering several times and once, when the nurses tried to get her back into bed, she flew into a screeching tantrum and fought them. Sometime during this scuffle, the young mother's drip ran out. No one knows how long she was without it.

That night, I woke to something like hell. Through the glass screen at the head of my bed, I could see five or six staff crushed around the bed resuscitating the young woman in a pool of light against blackness and eau de nil curtains.

In the morning, the neatly-made bed was empty and her nighty and few little things were in a large brown-paper bag in the bathroom labelled for her husband to collect. In the flurry, someone had overlooked the curtains around the bed: there was a great splash of blood, not yet brown, on their insipid hospital green. It seemed to me then that society had killed the young mother by insisting on keeping alive a demented old woman who could have died peacefully and easily and with propriety from pneumonia – 'the old man's friend'.

'Why don't they give her a needle?' I had said to a resident during one of the old woman's escapes. The way in which he misunderstood me was significant.

'Oh - we're not allowed to do that,' he said in a tone that revealed that he would have had no qualms about this sort of killing if it were only legal.

But I had meant a sedative, not a lethal jab. And the doctors' dilemma would have been to withhold treatment for pneumonia - not to take on the burden of killing.

This dilemma is still unresolved and the opinion leaders are mainly philosophers and lawyers - not doctors. The nurses (mostly women), who might contribute their views, are still constrained by their subordination to Cnidian doctors (mostly men).

## **RATIONAL PRESCRIBING?**

Where does prescribing benzodiazepines fit into the Cnidian/Coan traditions? BZD prescribing is by no means as rational as Cnidian ideology would lead one to expect and the use of a pill for non-medical conditions is not in the Coan tradition.

Their use looks particularly suspect when one realises the poverty of the evidence for clinical utility. Only 83 of the countless studies to evaluate the efficacy of benzodiazepines met the criteria of the Quality Assurance Project of the Royal Australian and New Zealand College of Psychiatrists for a meta-analysis. In severely anxious patients, BZDs were modestly better than placebo but for patients with low anxiety levels, they were no better. UK studies have failed to detect any superiority over placebo.<sup>21</sup>

Much benzo research has been designed not to find embarrassing evidence. It is whitewashing conducted by venal individuals at the invitation of the drug companies.<sup>22</sup>

Benzodiazepines are often used to treat life stresses that were formerly solved by interpersonal or intrapsychic processes and they are clearly used as a substitute for social intervention.<sup>23</sup> Many doctors admit that they have no time to explore psychosocial problems and cannot devise solutions but they can placate patients with a convenient prescription.

In other words, BZDs may be appropriately prescribed for symptoms but are not specific for complaints. One might as well offer the drug for anxiety aroused by a diagnosis of testicular cancer but neglect to refer the patient to an oncologist who could invoke surgery, radiation and chemotherapy.

If matching pills to ills is the nub of Cnidian medical practice, then Cnidian doctors may be said to use BZDs as the panacea for non-medical ills because they refuse to acknowledge the limits of their own competence.

Coan doctors, having a wider armamentarium, prescribe fewer pills. Thus, the eight doctors at the Eaglehawk and Long Gully Community Health Centre accounted for 52 per cent of the prescriptions at the area's largest pharmacy while a single private GP accounted for 20 per cent.<sup>24</sup>

The Cnidian argument that without technology, Australian medicine will sink to Asian levels polarises high-tech medicine and no medicine, neglecting the middle way. There is a third choice - a negotiated peace between Cnidian and Coan. I doubt that I will live to see it but that does not mean it is impossible.

# CHAPTER 10 HEAR ME TALKIN' TO YA! THE PATIENT AS CO-THERAPIST

I wake and feel the fell of dark, not day.

What hours, O what black hours we have spent This Night! what sights you, heart, saw; ways you went!

And more must, in yet longer light's delay.

Gerard Manly Hopkins

## **BLAMING THE VICTIM**

John was the elderly alcoholic who appeared on the *Coucbman Show* episode on benzodiazepines. He was weaned onto Valium from alcohol by a doctor who did not appreciate that if one drug is capable of substituting for another the second will be as addictive as the first. That is, John's presenting problem was alcoholism, not anxiety.

When I met him, he was sleeping on a mattress on the living room floor with his head outside the french windows. This was how he lived with his drug-induced claustrophobia.

As for his other symptoms, he said they are 'near as a touch to the DTs'. Nevertheless he played a mean game of billiards.

Having great difficulty withdrawing, John went to hospital several times where he was given a cocktail of psychotropic drugs in lieu of support. This is the same hospital where Joy was told she could drive although she was hallucinating.<sup>1</sup> The staff told him his problems were not due to benzodiazepines but to loneliness, advising him to sell his unit and enter an old people's home. During the period that I was writing this book, he killed himself using carbon monoxide from his snappy red yank tank.

None of the survivors in the TRANX support group doubt that his symptoms were due to withdrawal from benzodiazepines.

Many doctors claim that benzodiazepine sickness is difficult to diagnose because it is like the symptoms of the condition for which it was prescribed. I sense that they are invoking a liturgy here to absolve themselves from responsibility for patient suffering. Others are starting a process that ends by shifting responsibility to the victims.

Usually doctors who invoke diagnostic nihilism have not bothered to carefully record and analyse either the original condition or the recent symptoms.

How could the doctors have known whether patient symptoms represented a drug withdrawal syndrome when they overlap with anxiety and insomnia? The symptoms may be identified as:

- the emergence of the original disorder
- true withdrawal symptoms
- pseudo withdrawal symptoms
- the responses of an anxious personality to the stress of withdrawal.

According to Dr. Ashton, 'the benzodiazepine Withdrawal syndrome becomes largely a matter of definition.'2

Where the original condition was somatic, then the difference between the presenting symptom and new ones is obvious. It is not plausible to diagnose the re-emergence of original symptoms if the patient was initially a placid and non-anxious paraplegic, like Tom, but ended up as an irascible epileptic paraplegic with a multitude of symptoms never seen before. After sixteen years on Valium, Ned had all the familiar BZD symptoms but his presenting condition had been puberty.

My original symptom was waking up almost every second day with a sense of impending doom so intense that I was emotionally paralysed and this was even when the overt facts of my life gave me powerful reasons to be happy. I played with a fantasy in the hours between dawn and getting up, when I enjoyed my body's warm bed and I imagined cutting my wrists and dangling them tidily out of the blankets to bleed so that I would die a slow, gentle, quiet, warm, painless death.

I consoled myself with the rich clutter of my mind. The argument of Robert Graves's poem 'Death is the Twin of Sleep' was congenial to my humour and as regularly as I contemplated suicide, so I regularly chose Death's twin.

On bad days, I always managed to persuade myself that if I soldiered on, tomorrow would be a good day. I never, on good days, remembered that tomorrow was likely to be bad.

Kafka had been there. 'You've noticed, perhaps, that I haven't slept for several nights. It's simply the "fear". This is really something which deprives me of my will, tosses me about as it likes, I no longer know up from down, right from left.'<sup>3</sup>

Kafka called it 'the fear;' Virginia Woolf called it 'the horrors' but she experienced it as a wave.

Woke up perhaps at 3. Oh it's beginning its coming - the horrors - physically like a painful wave swelling about the heart - tossing me up. I'm unhappy! Down - God, I wish I were dead . . . I can't face this horror any more (this is the wave spreading over me) ... I doze. I wake with a start. The wave again! The irrational pain ... I become rigid & straight & sleep again & half wake & feel the wave beginning & watch the light whitening & wonder how, this time, breakfast & daylight will overcome it . . .  $^4$ 

My experience was tidier than Woolf's. I woke, usually a little before dawn, and The Horrors were there, like rain on the roof, and as inevitable. I forced myself to continue my normal routines of piddle, pills, TM, yoga, shower, and breakfast, always managing to get through the day's commitments. If I had no outside appointments, I sometimes went back to bed until it was time to make dinner.

After other experiments, a psychiatrist prescribed .625mg Ativan daily in December 1982 and I was on the road to medically raised doses during 1983 when he ordered three increases, bringing my dose to 3.125mg. This made me so dopey that I took myself back to 2.5mg. In March 1988, I halved this, seven months later I halved it again and, almost immediately, having difficulty getting my blurred vision to focus and my trembling hands to split an already small pill, I stopped altogether.

Many - or even most - medical discussions tend towards denial of the patient's experience, thus making the problem of diagnosis more difficult than it needs to be. Very few anxious people have the persistent, pervasive disruption that benzodiazepine addicts complain of.

The most obvious comparison is with DTs and some survivors are well able to make this comparison because one subset of addicts are those who were weaned onto BZD from alcohol, swapping one addiction for another. No one would try to disappear the DTs by saying that the condition shares this or that symptom with anxiety, lunacy or senility and is therefore imagined.

Siobhan Murphy and Peter Tyrer explain the long recovery period of benzodiazepine addiction as a period of learning to cope with stress after a prolonged period of letting the pills do the coping. The writers assume both that the patient was not coping before taking the drug and that the drug was effective. However, tolerance and addiction mean that all the drug is doing is making the patient sick. Many patients, for instance those who have been prescribed pills routinely for bereavement, have never been given a chance to demonstrate to their doctors whether they can cope or not.

I believe that those who always coped, continue to cope, and those who never coped, never do. Individuals intensify their normal responses.

Many people go to extraordinary lengths to meet their ordinary obligations. Todd, a youngish man, travelled to work during claustrophobic periods by forcing himself to endure a railway carriage for a couple of minutes at a time and changing trains at every station. This greatly extended the time it took him to get to work but at least he arrived.

Others gave up work only after enormous suffering and embarrassment and sometimes a demotion or change of duties on the way.

I have never been so organised as I was during addiction and detoxification. I have never needed to be.

Despite overwhelming data on inappropriate prescribing, doctors persist in the belief that benzodiazepines (and drugs generally) are prescribed for the purpose for which they are intended, ignoring the fact that advertising and detailers constantly train doctors to accept broadened indications for any drug's use. They also assume that complaints and diseases are correctly diagnosed. That is, doctors seem to believe that their system of matching ills and pills is working despite copious evidence that it is not.

When the benzo fuss became unavoidably obvious in Australia, Professor John Price defended their long-term use for long-term conditions – 'the nature of the conditions from which they suffer indicates that long-term treatment is appropriate. You wouldn't think of giving short-term treatment for diabetes or high blood pressure.'6

But it should be obvious by now that anxiety is not comparable to high blood pressure or diabetes. It may be either an organised disorder or an intelligible and legitimate response to a situation - perhaps where no other response is available.

Many of the conditions for which the drugs are prescribed, such as grief and stress, are essentially situational and short-term. And some situations, such as being young, negro, female, living in the inner city and needing family planning services, or being female and attending an outpatient service in south-east London, require social support, not medical palliatives. These indications are no clue to the patient's mental health or coping skills.

Looking back, one of the gratifying features of my experience was the persistence of my organising intelligence. The most public evidence of this is the regular photography reviews I wrote for the Arts and Entertainment pages of the Melbourne Age.

I was conscious of a troublesome humility in the face of other people's work and shame that I, riddled with self-doubt and strange sensations, should be in a position to criticise them. I deliberately adapted a few Hunter S. Thompson techniques to fudge my hostile judgements, becoming more personal and less authoritative. Although most of the reviews took double or triple the normal writing time, they are proof that I was coping.

Most women can sustain a witty conversation even though they have just noticed that their tampon has reached saturation point. I learned to abort impending jerks of my legs and scroll back hallucinations.

Once, when I hallucinated a cardinal red Fair Isle pattern on a companion's grey jumper, beginning at the shoulder and working my way down to the waist in bands, I said to myself 'This is a hallucination and you'd better stop it!' And I was able to roll back the pattern in the reverse order of its appearance, like computer image-processing. Mostly, I did not even actively override other bizarre reports from the interior just acknowledged them in one part of my consciousness and continued to live in the world I knew to be real.

Contrasting the incompatible messages from my various senses and sensory data with my rational knowledge became an amusing pastime. When hoards of thread worms began to flee down my fingers and exit under my nails, I did swiftly glance at my hands, just to reassure

myself, and went on eating my sushi. Ordinarily, the clock in my high-tech thermostat is about as noisy as a tiny quartz watch; during my most painful hyperacuisis, I used to go to sleep comforted, pretending I had a grandfather clock.

My routine conduct, when I reconstruct it, was startlingly normal. Some of my friends remember only that I was a bit edgy during those years.

Some obviously uncharacteristic conduct is not obviously druginduced. Narelle, a fastidious, slightly conservative dresser, found that she had somehow bought a pair of tarty raspberry suede thigh boots that she could not afford and would never wear. I, who love dizzy accessories, bought a pair of unflattering men's glasses on the grounds that men's things are more durable than women's and glasses are a precision instrument, not jewellery. Both purchases reveal almost masochistic disturbances of self-image.

I was supportive - as usual - becoming stronger, more cheerful and more resourceful according to the needs of those around me, but my benzo self had difficulty living up to my former self because it was so hard to pretend cheerfulness.

When my mouth hallucination drove me to seek psychiatric help, I was waitlisted with three psychiatrists. The first to have a cancellation was a woman who appeared to be original inner-city Australian - almost a dinkum Oz. I could not see any writing on the twenty or so dazzling white certificates on her walls but the smart frames matched the brilliant scarlet of their seals.

I was immediately suspicious. This woman was over qualified and came from nowhere!

I sway stiffly on the edge of a deep leather chair while I describe my hallucination and my fear that I am a candidate for manic depressive psychosis. Her consummate interviewing skills are as reassuring as the small-talk of certain good taxi driver & I know immediately that I can lean on her. But what is she?

Her bookshelves are stacked in double rows and she has the only copy of Married Love that I've seen in a private library. Against that, the ways and horizontal surfaces are hidden behind the soil of woolly hangings and bucolic pottery that suggests the weekend hippie.

Contrapuntal to my dialogue with her, my intelligence is running an argument with my paranoia: the woman is solid but obviously a woolly-minded liberal no doubt a Jungian and ultimately naive. Can I endure an hour of her?

I always aim for lawyerly clarity and precision in speech or writing so when anyone employs reflective listening, she risks distorting what I have said. I decide that teasing Dr. Dinkum to achieve a higher standard of correctness will be nitpicking and waste too much of my therapeutic hour, that reflective listening is inevitably approximate and that, for all she might be a fraud, she is kind, shrewd and a trier. I tell myself that my thoughts are paranoid and that I must on no account express them or do anything to detract from the purpose of my visit - which is to abort my impending manic depression with lithium.

Well, Dr. Dinkum does not believe in drugs. She feels they blunt the normal human capacity to sort things out. She does not prescribe anything but talking therapy. The more we talk, the more I respect her ability while yet wishing she were eclectic enough to use drugs where they could alleviate pain. At five minutes to the hour, we bow and separate but, as I am leaving she says I am welcome to come back if I ever feel like just talking.

I do, in fact, return when I need a shoulder to cry on about the rape of my mind and my dislocation from marriage and freelance writing into the nine-to-five workforce. Dr. Dinkum is a tad surprised when I tell her about the paranoia and blank certificate. I remembered twenty of them in a narrow alcove; there were in fact two sets of three (hers and her husband's) on opposite sides of the room. And they carry the usual inscriptions.

We talk for a couple of sessions and then she asks me what I am getting out of our hours.

'People come to me and I can see there's something wrong. But when I look at you I see a woman trying to make something of her life.'

## THE PATIENT AS CO-THERAPIST

Freud did not discover the unconscious: he laid claim to a concept that, appearing in writers from Plato to Charles Darwin, is practically self-evident.<sup>8</sup> Indeed, the appearance of the word in nineteenth century

English diaries and letters suggests that it was a much-used concept among the Victorian educated classes when Freud was born.

What Freud did, in addition to appropriating a commonplace, was to turn it into a means of control. If the unconscious is a cesspool of filth and menace, and only the psychoanalysed have access to it, then the uninitiate are at a disadvantage. Intentionally so.

At his most sanguine, Freud believed that the analytic relationship must entail a dominant and a subordinate; at his worst, he believed his patients were lying riffraff - a view apparently shared by many of his followers, including the medically qualified serial killer, Dr. Harry Bailey.

The psychoanalytic use of the unconscious for dominance aggravates Cnidian lack of respect for human beings. Patients exhibiting nervous symptoms, sometimes even patients expressing normal emotions, join children and lunatics in the category of creatures not to be trusted.

But the brain, even when it really is harmed, is splendidly various. Olivier Sacks describes a delicious incident when a group of brain-damaged patients laughed convulsively at the President's speech on television.

Some were suffering from global aphasia - the inability to understand words as words although able to grasp meanings through non-verbal cues such as tone of voice, facial expression and posture. By contrast, one had tonal agnosia, an inability to understand anything but the literal words - the expressive voice tones are lost. While the normals thought the President's speech quite charming, well delivered and impressive, the damaged found him ludicrous and untrustworthy.<sup>9</sup>

I began to develop something like an aphasic alertness to nonverbal cues in late addiction - say halfway through my fourth year on Ativan. Instead of seeing a person as a complete picture with every detail available, I would light on a single detail, a false timbre in the voice, tense mouth or lifted shoulders telling me that the speaker was lying or hated me. Occasionally, I am again aware of this depleted perception with heightened details - I suspect it is how normal people respond to their kind most of the time.

The brain has an extraordinary capacity to monitor the person. The benzodiazepines dull the individual's capacity to receive and process messages from the external world while simultaneously setting up a

tumult in the *milieu interieur* that constantly attracts the sufferer's attention inwards. Somehow, this does not impair self-consciousness and may even sharpen it into a constructive egoism.

'I learned to act while I was on Ativan,' said Caitlin, who had been on the drug between the ages of eighteen and twenty-four. (When grumbling bowel began to predominate over her other symptoms, her doctor increased the dose.)

I was always aware of my monitoring intelligence, often comforted by it and sometimes amused. It even controlled my paranoid phase. As I passed into 1.25mg withdrawal, and then beyond zero, my intelligence sometimes had to stop me going to an open door to listen to what people were saying because my paranoia said they were gossiping about me.

I developed a theory about paranoia itself and tested my ideas of the unconscious. Paranoia is a condition of intense alertness and anxiety for self-preservation, in which cues are selected unduly from their context, tempting the observer to make sense out of obtrusive details that very likely have no sense.

I mentioned the intermittent muscular weakness that sometimes made me unable to turn a key in a lock or turn on a tap and made my handbag now almost intolerably heavy and then surprisingly light. Sometimes the weakness almost overcame me like a fainting fit.

I was shopping in Victoria Market, my hand held out for change, when I had a tiny fainting. The dark-eyed, solemn-faced woman behind the bread counter seemed to have pressed the coins heavily into my hand and the hand seemed to falter under their awful weight

I both knew that the sensation was in my palm and wrist and knew that the woman was trying to impress a message on me. In a French policier such a gesture would have been accompanied by a sidelong glance at the informer in the crowd.

Days later, weeks even, I was possessed by the woman's contentless message, for her gesture persisted independently of my rational control.

Flamboyant paranoia strikes us as unreasonable because it wilfully misinterprets cues, it unjustly attributes motives and intentions to totally innocent and even irrelevant people and it tends toward defensive violence. Viewed with one foot in the nuthouse door and the other on a banana skin, paranoia seems to be a disorder both of perception and of fight and flight - an inability to sieve cues feeding into an instinct for self-preservation that is already running wild.

I had discarded the cesspool model of the unconscious years ago, while I was anaesthetised for my third abortion. Going under whilst trying to plot a topography for the conscious, preconscious, unconscious and censor, I woke up to the already formed decision that the problem itself was codswallop.

During withdrawal, I came to the belief that there was no unconscious - only areas not immediately monitored by the conscious. That faculty could only take in relatively small samples of experience at a time - like a periscope that moves within a very circumscribed range or an old-fashioned mobile X-ray screen that can be rolled backwards and forwards over a patient's body to give a continuous but limited view of what is inherently viewable.<sup>10</sup>

Once computers came in, I had a ready metaphor with all sorts of functions like a monitor, memory, and scrap that made material differentially accessible.

Which brings me to where I have been leading you: **the patient as co-therapist.** 

A lot of information that is accessible to patients will only become accessible to doctors if there is good communication between the two parties. And the patient is not teetering over a festering cesspool but possesses a computer essentially like the doctor's own. Admittedly, some are more sophisticated than others and are loaded with more expensive software.

#### Stink

Stink was a peculiarly distressing symptom that appeared early in addiction - on 9 September, 1986, to be precise. I became aware of a foul smell during a crowded and exciting meal to celebrate the opening of a photography exhibition. I blamed it on my leather dress but it persisted well after the dress was cleaned. It was not an organic smell as of crutch or armpits or farts or even of rotten teeth but the sort of chemical smell that comes off alcoholics and people chronically on medication such as the now obsolete Alupent.

I probably suffered more distress from Stink and invested more time chasing its cause than I did with any other symptom. I could conceal the fact that furry creatures were chewing my ears but I could not conceal Stink.

Friends showed visible distaste and strangers got up and looked for a seat further down the tram. Dan kept me literally at arm's length during the Premier's Literary Award dinner by prodding my shoulders if I got too close. Eamon told me I was a beautiful woman and flung himself on his knees beside me, where he could comfortably chat. Toby conducted a long conversation sagging at the knees to get below the range of my breath. My clothes began to collect Stink until opening my wardrobe became a reminder that I was sick.

Eventually I found myself referred to a physician, married to a psychiatrist, who had on his walls a picture of Freud and a picture of Blake.

'Oh William,' I thought, 'you have fallen into bad company!'

I went through the long history of eliminated causes: my teeth were not rotten; my digestion not bad; the smell was intermittent but not related to my lung infections; it did not relate to changes in medicine nor to particular foods; I was not alcoholic; I feared liver disease or diabetes but did not have them.

Well aware of the venerable history of smell in diagnosis, <sup>11</sup> I vaguely hoped to see an experienced diagnostician go through a fascinating algorithm and come up with a solution. *Eco la!* 

What I got was a display of rampant arrogance with tiny smirks and simpers of contempt. From time to time, and apropos of nothing, the man said 'We don't do vaginal examinations here.' I was bemused. Where did the vagina come into all this? I felt that I was being played with by a pretentious dickhead. Then I saw the doctor's reasoning. I hope I can get it right. It would go something like this:

- the unconscious is a cesspool
- people are at the mercy of their unconscious
- people never say what they really mean because only analysands know what they really mean
- all women think their vaginas stink
- a woman who claims to have an odour originating in her sweat and breath really means that her vagina stinks.

Of course, it might go like this:

- all women are seductive
- particularly with their doctors
- a woman who comes to a doctor with a complicated and implausible story probably has hanky panky in mind

- doctors need to be very careful with women patients
- especially dashing cocksmen like me.

At some point in this charade, my tormentor realised that he was not dealing with Mrs. Kerfoops but with Beatrice Faust and began making asides about me in the third person . . . 'She's not going to tell me.' 'She must be a very private person.' From being merely patronising, he developed the alert interest of a dog that smells menstrual blood.

Curiously, practitioners who most believe in the unknowability of the Unconscious will persist with interrogations as if information is readily available to the patient who is withholding it wilfully. Instead of patiently accessing my unconscious by association, dream analysis and astute probing, Dr. Dickhead began to coerce me into validating his fantasy.

'Where did you say the smell was?'

'On my breath and in my sweat.'

'Come now, where did you say the smell really was?'

'On my breath and in my sweat. Lots of my friends remarked on it: burnt toast; the Caulfield sauna when everyone is popping amyl; noxious fumes; ketonuria; varnish; vinegar.'

'You choose your friends badly.'

I was tempted to misbehave ... to burst in hysterical laughter ... to spit and throw things ... to match his lunacy with a craziness of my own ... to provide the doctor with grounds for believing I was as *non compus* as he was inciting me to be.

But I managed to be patient. And courteous. And suddenly I was very tired. I was consoled to notice that while Dr. Dickhead was relishing his malice he did not observe that he had spent over seventy-five minutes harassing me. Eventually other patients in the waiting room began to mutter and get up and leave.

Descartes did not resolve the confusion about the brain's relation to behaviour or conduct - he merely tidied the problem up pending more refined research. One hundred years ago, Freud did not have enough information on the sex hormones, let alone the neurotransmitters, to resolve his *Project for a Scientific Psychology*. He was forced to switch

between varieties of reductionism.<sup>12</sup> The status of the ghost in the machine is still arguable but the computer analogy permits us to carry the argument several stages further on.

The conflict between the belief that disordered behaviour stems from disordered brain function and the belief that disorder is in the psyche can be described as a conflict of form and content or of brain hardware versus psychological software.

Parkinsonian tremor and rigidity was sometimes interpreted as a manifestation of suppressed hostility until it was traced to shortage of dopamine, a neurotransmitter in the brain. Thus, a disease that had been seen as a problem of software or content came to be seen as a problem of hardware or form.

A similar evolution has occurred in accounts of obsessive compulsive disorders such as trichotillomania which forces the sufferer to pull strands of hair out by the roots until s/he is bald. It also applies to other disorders of the grooming instinct such as hand-washing that previously resisted efforts to reprogramme with new software but responds well to simple adjustment of the hardware with drugs such as tricyclic antidepressants.<sup>13</sup>

There has always been less moral opprobrium attached to defects of the hardware than the software because free will and moral responsibility are usually located in the software. Thus, nineteenth century homosexuals were eager to prove that their condition was biological, constitutional or hereditary because they could not fairly be blamed for what they could not control.<sup>14</sup> It was left to Gay Liberation to say that homosexuality was neither a defect nor blameworthy.

Traditionally, individuals with clear neurological damage, such as the personalities described by Luria and Sacks, have been trusted to reflect on their conditions and report back because they were clearly damaged but not mad. 'Exploring the fine grain of the construction of psychological faculties has increasingly forced scientists to enlist the experimental subject as co-investigator . . .'<sup>15</sup>

Benzodiazepine users have been denied this collaboration. Our condition is clearly biochemical in origin but we are blamed as if there is something psychologically wrong with us: `. . in contrast to the neuropsychological approach, neither psychiatrists nor psychotherapists take the experiences of psychiatric patients as they report them at face

value ... In practice this means that nothing much that an individual has to say carries the normal weight in the clinical context.'16

Benzodiazepine scandal should destroy the myth that free will and moral strength have much influence on addiction. If the survivors are listened to, it could also lead to a reformulation of the ghost in the machine problem.

The success of neuropsychology has offered a new legitimacy to the notion that our internal mental life can be investigated scientifically. There are, however, two important implications of seeing disorders of form as neuropsychological deficits. One is that not all internal events should be interpreted in terms of motives. Some will arise as experiences; and to investigate these we need to describe them in a detailed and accurate fashion, rather than try to 'interpret' them.

The second point concerns the question of who does the describing. Detailed and accurate describing is not something one expects of the 'insane'. But subjects with environmental dependency syndrome, Tourette syndrome and other neuropsychological syndromes are not seen as insane, even though the experiences they describe may be highly unusual . . .  $^{17}$ 

Now that neuropsychologists have begun to enlist the subject as coinvestigator, psychiatrists might profitably do so.

### **Women's Troubles**

Anzac rolled over to his side of the bed.
'I'm sick of this,' he said.
I have been bleeding for twenty- three days.

Many BZD survivors and some researchers report unusual menstrual symptoms<sup>18</sup> but our knowledge of the female reproductive process is so curiously uneven that the symptom is hard to interpret. Heavy, prolonged bleeding can be caused by intra uterine contraceptive devices, malnutrition, aging, fibroids, depo provera, pelvic inflammatory disease and benzodiazepines.

My menorrhagia began months after - perhaps as long as a year after I began taking amitriptyline and Valium for The Horrors and continued through the interval between dropping these drugs and commencing Ativan. The case for connecting my menorrhagia to benzodiazepine use fails on a standard algorithm: the continuation of the symptom despite discontinuing the drug and the numerous possible causes leave me with a score of +2 (out of a possible +22 or more), which is in the 'unlikely' range.<sup>19</sup>

My personal experience of menorrhagia, then, tells us nothing about benzodiazepines but something about Cnidian medicine.

The general case for connecting complaints about menstrual disorders with this family of drugs certainly deserves rigorous scrutiny. It may not be forthcoming. In general, less funding goes to research into women's health than into disease generally. The vast bulk of female-centred research is into reproduction. Even so, many - perhaps most - advances in reproductive knowledge have come from veterinary research for agribusiness. Since menorrhagia represents only a trivial inconvenience for some men and understanding of the disorder is not likely to benefit farmers, there is little incentive for research. Although women's fertility presents a fascinating challenge to scientists concerned about overpopulation, our disorders, by their very widespread occurrence, may seem commonplace and trivial to Cnidians.

I had a curettage that revealed only minute fibroids - insufficient to account for the volume and duration of bleeding. I suspected a hormonal cause but my gynaecologist's armamentarium consisted only of D & C and, if that failed, hysterectomy.

No.

I telephoned a research pharmacologist in the medical faculty of a prestigious university. I chose her because she is a lesbian feminist with a fairly low threshold of scepticism about androcentric medicine. She recommended me to a professor in her own department.

On my second visit, to get the results of a sonar, I found myself kept waiting an hour and a quarter for a two o'clock appointment. Meanwhile, the other patient in the waiting room was foiling my attempts to read.

She was large and raw-boned and dowdily dressed, apparently friendless and very vulnerable. She seemed to have no past beyond last Thursday. A second woman came in, wearing twinset and pearls - in 1981! Then a third - nondescript.

Hoping Miss Lonely Hearts would strike up a conversation with them, I returned to my book but I was disturbed by a radiant lass in the full ensemble of a 1950s bridesmaid: lemon ballerina with a Christian Dior built-in bra, dyed-to-match satin stilt-heel shoes, a dilly bag and curvette of self fabric all dyed to match, and flawless maquillage. Rustling her bouffant skirts, she shunted me into the comer of the sofa.

To avoid laughing in her face, I studied her feet. Size ten and stretching the satin. Awful ankles. Five o'clock shadow on the calves. Inching my gaze around the carpet, I found they all had large feet and awful ankles. Knees ungainly too. Hands and wrists to match. And they were all carrying naked cosmetic purses.

Professor Trizz cantered through my consultation.

'There is nothing down there, Mrs. Kerfoops!' he urged. 'Nothing down there!'

Well, there was something down there and it was bleeding at a biblical rate. Although I had never suspected cancer, I had expected a hormonal investigation. Drooping under Ativan tiredness, I did not feel up to forcing myself on an eminent professor who was clearly not interested in women's troubles. I left gracefully.

On the stairs, I remembered that Professor Trizz was also the top man in a sexual reassignment team. Men get all the breaks - even at the gynaecologist!

## Depersonalisation

While menorrhagia was probably a sign of aging, most of my other symptoms fit Dr. Ashton's list very neatly.

My hands are not my hands

Lying on my back in bed reading - an obscene and unhealthful posture, according to Takuo - I cannot help but observe the hands holding my book.

They are very familiar to me: I know them intimately.

They are very long and tapered because the individual fingers are long and tapered. The thumb is somewhat short in proportion and set low down from the fingers so that it contributes very little to the breadth of the fingers, but something to the breadth at the base of the hand which then contracts into a childishly narrow wrist. The hands are pink underneath and white on the backs.

I try to keep the nails long to heighten the effect of tapering but I am so unhealthy that they split and craze more often than not. On the

back of the left band are tiny scars where, years ago, I covered my face as my husband threw all the breakfast dishes at me.

Once, for no reason that I could see, my father - who never spoke to me unless it was to say 'Come back and close that door quietly!'- laid my hand out on the table cloth and laid out his own beside it to demonstrate that they were the same in all respects except size and colour: mine a childish version of his, which was large and virile, despite its taper, and burnt a dark brown from years of working in the open - building fences, breaking horses, delivering lambs. Even the knob on the outside of the wrist was the same.

He said I had pickpocket fingers. Blanche and Freda said I had piano fingers. I knew, from quite early on, that they were all wrong.

When I took my newborn son to see the Vincents, the first thing they did was to pull his tiny arms from the blankets and unfold the little curled fingers. Finding that they were blunt, the hands square and the wrists thick, they said 'Oh well, he's a very nice baby' and took him away to a nest of pillows on the bed where Thirza, his great-great-aunt, was dying delicately in floral sheets.

Yola once told me that she had got through a dull two-hour meeting by looking at my graceful hands. She urged me to have them photographed or sculpted. Bernard, on meeting me for the first time, held out one of my hands (it doesn't matter which one) to an assembled dinner party and said 'Isn't this a splendid hand to hold a penis?' 'Hilary called me 'Iseult of the White Hands' the night I relieved him of his virginity.

Now and then, as I looked at the hands, I would put the book down and scrutinise them thoroughly from behind the soft circle of the reading light. I was obsessed by the idea that they were not my hands, that if I could creep my glance up the arms slowly enough, I should find the gap that proved they did not belong to me. I imagined them ending in a lace frill - like an Erté glove advertisement.

And yet they were mine - in a sense. I could move them, examine them from all angles and somehow, although they were not really mine, I could instruct them to pick up the book again and permit me to go on reading.

The hands-not-mine puzzle of 1985 became a face-not-mine horror, present during addiction but increasingly pronounced in 2.5mg to 1.25mg withdrawal. With infinite slowness, the concern with illness

became a separation from self. I referred to the face in the minor as 'she'. 'She's terribly sick. She's got something awfully wrong with her. Look at her ... so sorrowful, so tired! She's dying.' This unhappy narcissism became almost obsessive in Autumn 1988, gradually receding when I went from 1.25mg to zero.

## 'We Can't Have You Looking Sorrowful'

TRANX support staff, both professional and volunteers, say that they can recognise the characteristic face of addiction and withdrawal: pudgy with slack muscles and heavy shadows, lead coloured, flyaway hair, sorrowful expression and a tendency to immobility or even rigidity that prevents feelings coming to expression.

Addicts are often unable to smile - or if we smile, it is only at our own internal states and idiosyncratic responses rather than at shared social cues. Since we also have a tendency to listen intently as if we are in the dark, without making eye contact unless we are forced to or unless we make a deliberate effort, social interactions are warped.

Benzo junkies seem more spaced out than we actually are. Contrariwise, we can seem more feeling than we actually are: it is possible to get the visible motions of laughter or sorrow without visceral response so that we do not feel the emotions we express.

In September 1989 the technician at the Respiratory Laboratory, whom I have known since 1966 and know socially besides, saw an immense and pleasing change in me from our last meeting in December 1988: she remembered me as both very ill and 'judgemental' in 1987 and 1988. Not only that, she was Bible-oath convinced that I had been walking with a stick.

I was beginning to develop what I now know to be the characteristic BZD face during 1984. When I was not suffering from sinus or flu, I had difficulty explaining the black arrowhead shadows at the comers of my eyes. They seemed to be the shadows of illness - but I could not claim to be ill. At this time and into first stage withdrawal (from 2.5 to 1.25mg) the skin on my face was fragile and oedematous enough to take a fingerprint.

When I had my portrait drawn in March 1985 for a Bicentenary women's exhibition, I could not smile convincingly. I was able to sit motionless for hours at a time, to the artist's delight, but found my

public face kept slipping into the characteristic BZD sullen depression. For eleven years, I had had an impressive stillness from practising TM but now I was aided by the BZD torpor.

The artist was so disappointed with her first sketch that she asked for a further sitting – 'We can't have you looking sorrowful!' she said. But the second was little better.

A series of photographs taken April 1988 are even more curious: I was, by then, living in my newly renovated house, gently involved with a garden, and feeling hopeful. I was being photographed by Pavel, a cheerful, guileless man whom I respect for his contribution to art in Melbourne and who, by his effervescence, always made me feel optimistic. I thought I was smiling broadly - even vulgarly - all over my face and halfway down my back.

When I saw the proofs, the faces were quite solemn, in no way reflecting my satisfaction.

The discrepancy between what I strongly felt and what my face was able to express was startling. I was acutely aware of the effect of the benzo face on other people and dreaded the variety of fearful and hostile reactions it could induce.

When I returned to the 9 to 5 workforce in 1988, I trained myself to smile. It was crucial to draw the lips away from the teeth. If I did not do that, I could not be sure that I was visibly smiling. Whenever I found myself alone in the lift or in empty corridors or comers, I repeated in my head 'Crank up a smile! Crank up a smile!'

It must have been fairly effective because, although people recognised my fierce temper, I was also seen as 'chirpy', 'bubbly', 'cute'.

Many survivors have reported this frozen and sorrowful face - one more celebrated than the rest. Two years before his suicidal depression, William Styron was prescribed Ativan at three times the normal dose and told he could take it 'like Aspirin'. He replaced Ativan addiction with Halcion and was taking excessively large doses, especially for someone of his age. He describes his subsequent illness as depression triggered by benzodiazepines and traces its stages in a classic document, *Darkness Visible*.

November wore on, bleak, raw and chill. One Sunday a photographer and his assistants came to take pictures for an article to be published in a national magazine.

Of this session I can recall little except the first snowflakes of winter dotting the air outside. I thought I obeyed the photographer's request to smile often. A day or two later the magazine's editor telephoned my wife, asking if I would submit to another session. The reason he advanced was that the pictures of me, even the ones with smiles, were 'too full of anguish'.<sup>21</sup>

I made one curious discovery: laughter is not an emotion. Although my normal emotions were muted to nullity, I could always laugh. I came to the conclusion that laughter is a function of the intellect.

## **Garlic, Chocolate and Drains**

By Spring 1986, I was forty-seven years old, menstruation was regular but becoming sparser, and I was losing my sense of taste and smell. I had a vague idea that these processes were connected - although the connection between hormonal fluctuations and olfactory sensitivity is not clearly established.<sup>22</sup> Why should I connect the loss of savour with a drug I had commenced over three years earlier?

The first loss of taste had been sudden. I had recovered from the flu and was looking forward to a substantial, tasty Italian meal to set me up. When the rich savoury mess of veal and cheese and tomato and oregano reached my table, I took a few mouthfuls and had to stop. I was hungry and the food was hot, fresh, and looked welcoming but I could not force it down.

I felt like a baby that has crawled over an experimental glass trap in the floor: it cannot identify the menace or explain why, but it will not venture further. I felt ridiculous but I could not do more than eat a little plain bread. As soon as I began to cook only for myself, I ate as plainly as possible.

I had enjoyed food and liked my own cooking best of all - having enough left over from a dinner party to enjoy the next day was the cook's small, cherished indulgence. But my little progress tastings began to tell me that my cooking was bland or boring so I doubled the cloves of garlic in a bolognaise or sloshed liqueurs into a summer pudding, and the wrinkled noses and pursed lips of my guests showed me that the flavours were extravagant. I began to lose my zest for cooking and my confidence in myself as a hostess.

In any case, my catastrophic tiredness was making the whole ritual too demanding. One night, two years into addiction, having dragged through the usual dinner-party timetable, I was loading the dishwasher with all the cooking things when I found myself slumped on the floor like a puppet with cut strings.

I knew that if I moved quickly, I had time to telephone the guests and put them off but I could not flog myself to quick movement.

I plodded through the remainder of the kitchen routine, showered, dressed and saw the dreary meal through to the end. I think that was the night when I noticed Marabel spitting a gobbet of *gateau de marrons* into her hanky. I had measured in all the ingredients and, finding myself with half a block of cooking chocolate left over, had been overcome with a confused 'what the hell' feeling. Instead of putting the nub away for next time, I had chucked it into the pan. The result was an inelegant stodge.

This story is so typical of everyday BZD confusion that it raised a palpable ripple of sympathy in the support group. Everyone had been there. Even some of the men.

Although the loss of taste made my life more drab and caused me social difficulty because of cooking, my sense of smell was intermittently acute. I delighted in smells ... flowers ... my herb garden when I watered it at night ... my native plants ... men's armpits.

I cannot find any pattern in this selective waxing and waning and the intermittency of it all prevented me from seeing it as a disorder. My greatest impairment lasted from Spring 1986 to Spring 1987 but it was present before and after that.

I first experienced smell panic in Tokyo during 2.5mg addiction, January 1985. The Japanese traditionally practised incense blending as an art and perfumed robes with delicate smoke but being extremely clean, they did not experience the western need to disguise effluvia with heavy perfumes or share the western enjoyment of scented toiletries. All fine Japanese cosmetics, scents, soaps and lotions are perfumed, very lightly, subtly and almost unidentifiable. I used to be able to isolate mandarin, mushroom or vanilla in the unguents whenever I had a facial with western cosmetics but Japanese perfumes were too subtle for my analysis.

Finding the Hotel Okura's line in luxury giveaways irresistible, and its aftershave as attractive as its body-lotion, I had rubbed my hands with aftershave.

Sitting in the kabuki, delighting in Utaemon VI, then aged sixtyeight, exquisitely playing the role of an eighteen-year-old girl, I found my delight was subverted by panic rising like bubbles in a kettle at a rolling boil.

I could not attach the panic to anything until, when I was becoming frantic, I realised that it was related to smell. The almost imperceptible perfume on my hands had become as disgusting as a tomcat's spray or the ripening sweat on a fat woman's longworn brassiere. I held on until interval released me to go to the toilet and, literally, wash my hands.

Another time, early 1988, that is, early in 1.25mg withdrawal, I was set to go out to dinner when I found that my elegant new-from-the-mains-in kitchen stank appallingly. I sniffed around for the source of the stench, wondering whether I had been falsely economical in using rich mulch in my plant pots instead of buying a hygienic potting mix. My bemused son could smell nothing and watched me with his smiling 'Oh Mother...!' look.

Finally I decided that the peculiarly noisome smell could only come from the drains. Again, the effect went beyond disgust to panic. I cried off from my invitation and frantically began to purify my drains with boiling water and cans of caustic soda.

I had a few more of these spectacularly silly episodes before I noticed that my hyperacuity was going away round about September - December 1989 after a year of zero withdrawal.

This particular form of olfactory hypersensitivity among benzodiazepine survivors is mentioned in the literature but I only found one doctor who acknowledged that sufferers can smell things that other people cannot and he thought the phenomenon trivial.

# Red / Green, Stop / Go

Alan had the intent single-mindedness that makes people go on repeating the same behaviour, even when it is demonstrably wrong, because they are simply unable to switch off. He would stop the car at the green light and go on the red. Holding an eight-month-old baby on each knee, I did not want to scramble out of the car while it was stopped.

I calculated that there were five stops between us and the University Creche, that traffic was thin and that we were travelling slowly enough to avoid trouble. Alan was a notorious pill-popper. The year was 1966.

I stopped at the intersection of Franklin and Elizabeth Streets. Knowing I could not read the lights, I repeated to myself, 'Red for "stop" and green for "go"!' I sometimes used to make this work if I managed to contain the formula at its most basic. But there are four-times-three lamps at each of four comers. If I moved my eyes sideways or diagonally opposite, I became confused and unable to concentrate on the signals I intended to follow.

Joy, seeing my hesitation, took me maternally by the shoulders, faced me straight ahead, and gave me a little shove. Mostly, I was by myself so I ended up following the direction of the crowd. If the street was really deserted, I looked both ways and crossed when it was safe. The year was 1988.

My traffic-light difficulty occurred in withdrawal but it seems to be a variation of an earlier problem involving dichotomous choices. During addiction, I had extraordinary difficulty with a simple k2 p2 knitting pattern and when I asked Merle to help me, she was politely bemused at the elementary nature of my mistake.

I slowed down the supermarket queue or the line of passengers at the ticket desk in the tram because I could not immediately select between coins of different sizes but the same colour. Perhaps because of the greater size difference between one and two cent pieces, they never caused embarrassment.

## **Reckless Courage**

I have always been capable of courage. One of my warmest memories is from the 1972 campaign to open the administrative division of the Victorian Public Service to women. I took the sunglasses and camera away from a Special Branch stringer while Sandy photographed him.

Normally, I would have a visceral response before and after my little adventures because my courage then was a triumph of will over fear. Now I felt no fear at all. Fear is not anxiety - it is an intelligible response to the real world. It is possible to have enormous anxiety and no fear. And I did.

In Autumn 1986, my husband and I had quarrelled. He did a hit and run - made a slighting remark and left the dining-room immediately. I followed him into the kitchen where he picked up a wine bottle and said 'I'll bash your face in! That's what you want, isn't it?'

I knew he had been having aggressiveness training and I suspected that this was a less than spontaneous response. I also knew that one must never turn one's back on violence.

I walked up to him, took the bottle out of his hand, placed it on the bench beside him and said 'You don't want to do that Anzac - you'd lose your practising certificate.' Then I walked away - slowly.

I had faced up to menaces before and succeeded but I had always had to master my own fear and the effort always left trembling inside. This time, I felt a mild amusement at the relief I had seen on my partner's face when I saved him from making good his threat - but I felt none of the reaction that I would normally have expected. I felt no fear. It was uncanny - but I could not even feel the uncanniness of it.

Three years later, risk-taking had become a habit. When I wanted to stop a tram, I stood on the tracks and wig-wagged my arms. I moved drunks out of my way at the bank and was not distressed by strange men in empty buildings or dark streets.

About this time, I found myself walking exhausted to Elizabeth Street from the Yarra Bank Platform when I saw a shouting group of Australian teenagers chivvying a solitary Asian boy at the end of the lonely underpass. I was still in that state of benzo exhaustion when walking any distance at all is an endurance test.

Knowing I would have a hard decision to make at the end of the tunnel, I continued to walk stolidly in my stiff, tired, benzo gait. This brought me to the space between the lead hoon, a screeching girl, and the trembling boy. I had still not decided on a tactic.

By then the teenagers had spread out and down the steps leading to the street and the boy was frozen against the rusty white-tiled wall. I could see the orange-skin pores on the girl's pallid, puffy cheeks.

I was opening my hands to give her a palm-flat, stiff-armed shove in the chest when something about my stare must have distressed her for she broke away with a little swear. A couple of ticket collectors had been attracted by the noise and the rest of the group melted away. I did not notice where the boy went or even when he fled. As I trudged to the chilly basement where *The Snake Pit* was showing, I was surprised by my lack of fear.

This inert courage indicated the loss of a proper sense of self preservation. I did occasionally have startle responses but often they were inappropriate.

My reckless courage changed somewhat as I began to speed up in zero withdrawal. Bruce is what you could call an anxious extrovert: he talks a great deal and has a Hobbesian view of life. When the job I was doing was advertised, he applied for it - as was his right. He also began to harass me whenever we met.

'You're not going to get that job, you know. I've got one baby and another on the way!'

'You'd better not let me meet you on the stairs - I'll chuck you straight over!'

'Jeeze - if I meet you in the lift, I'll stick a shiv in you!'

I put up with this for several weeks. Frankly, I was so drugged that I had no gut response to any of it. But rationally I knew it might not have been me but a younger, more vulnerable woman who would be demoralized by the chivvying. I had already decided to stop it when Bruce started a new tirade in the lift.

He had taken possession of a comer and was standing open from the nose to the knees with his arms resting along the bars. There were perhaps five other people with us - he never bothered to keep his nastiness private. Perhaps he thought it was a joke.

I knew that his testicles were exactly my leg length away and swung my foot in a splendidly precise arc. When my chisel-toed shoe was at about level with his knee, I had a little think.

At that point, everyone in the lift was visibly on my side. But Bruce doubled up and swearing through his tears would create conflict - they were bound to feel sorry for him. I contracted my leg fractionally and brought the sole of my shoe to rest over his zip with a millimetre to spare, at which everyone burst out laughing.

The whole incident was totally spontaneous and could only have lasted seconds but it seemed a most leisurely and rational process. Bruce never harassed me again.

The speed, co-ordination, and wisdom of this encounter was entirely new. Never graceful, even at my best, I was often paralysed by the moral decisions involved in attack or defence. I began to feel that I was experiencing that integrity of the body that footballers and boxers must feel. That men must feel.

## **Speeding Up and Slowing Down**

I had always typed like an arthritic chook so I enrolled in a typing refresher course during winter 1986. Crazy speediness created extraordinary patterns of errors. The following December, when I was writing Christmas cards, I found my writing scrunched up in upper left corners as if the carriage-return bell had jammed on an old-fashioned typewriter and the letters had overtyped.

I kept speeding up and slowing down.

I made grotesque spelling mistakes by transposing syllables, able to recognise that they were wrong but unable to see precisely how, since all the syllables were *there - Neurocholpsyogical Tocolxiogv* is a book by Hartman. I tried to type 'erection and ejaculation' and produced 'erejtion'. Sometimes I had to play with the words on a blackboard to identify what was wrong.

In Spring 1988, the photocopier was much too quick for me. Trying to keep up with it, I felt like Charlie Chaplin in *Modern Times*. Sometimes I could write as much in five speedy minutes as in twenty or thirty normal minutes. I would write furiously and check my watch and find that only a minute or two had elapsed but the results were indistinguishable from slow periods. The fast work was as neat and lucid as the normal work. These episodes could occur two or three times a day.

I seem to have passed Spring 1988 at a gallop - apparently running upstairs and downstairs and walking very briskly everywhere. I

explained it to myself as a compulsion to prove myself effective in the 9 to 5 workforce.

I now realise that the speed was very often a subjective perception and that I was probably not moving exceptionally quickly. I have not seen references to speediness nor heard support group people mention it ... perhaps this symptom is peculiar to me?

I could go on ... and on ... pointlessly. There is no Luria or Sacks to bend his scientific imagination to the experiences of benzo junkies. It will perhaps be more profitable if I tell you a little about the doctors I did come across.

# CHAPTER 11 NO ROOM ON THE RAFT

You talk as if there's some cache of knowledge out there-there isn't!

Dr. Ron Elisha

### WASTEPAPER BASKET DISORDER

The illnesses of addiction develop imperceptibly and the symptoms are so intermittent and so varied that it is like being slowly poisoned. Think of Ingrid Bergman in *Notorious* becoming gradually more ill but with no particular complaint, her deterioration perceptible to observers but not able to be diagnosed. This malaise was susceptible to unpleasant labels, like hangover, and the climax of the film hinges on the hero's ability to discriminate between an invalid and a drunk.

In the years I was on Ativan, I did not find a Cary Grant to bend his handsome face on me and lend me a strong arm when I could scarcely stand for benzo exhaustion. Nor did I find a doctor astute enough to make the distinction between malingering, neurosis, and BZD addiction.

Various helping manuals set up a scenario - inspired by economic rationalism, no doubt - of a life-raft adrift with insufficient space for a diverse lot of survivors: a politician, a poet, a poop, a paedophile, a priest, a poultry farmer, a publican, a prostitute, a pregnant mother of five and a duly qualified medical practitioner. Who will you throw off?

As I realised that my search for help was fruitless, I also realised that I could not find any justification at all for saving a doctor in preference to anyone else.

The course of addiction - perhaps especially with the short-acting benzodiazepines - is a series of vicious spirals. The sufferer, who was sometimes already anxious, is further afflicted by a heterogeneous group of symptoms - including anxiety - that come and go intermittently, making it difficult to know where to begin seeking medical aid and for what.

The patient latches on to something and embarks on an increasingly desperate search for a diagnosis. Visits to the GP lead to visits to the pathologist that yield nothing. The negative results lead to more or less overt contempt and abuse as the doctor finds a routine label for the patient: hypochondriac, malingerer, obsessive, neurotic, menopausal and so on.

Some thoughtful medicos call this 'wastepaper basket disorder'. Apparently doctors no longer practise diagnosis as an adventure in detection; they function by repeatedly attempting simple pattern recognition. If the patient does not present symptoms that match an existing pattern, and pathology reveals nothing, the doctor dumps the problem in the wastepaper basket.

There is no holding file where s/he can acknowledge that the patient does have a problem that has not yet been identified, but that will eventually have to be diagnosed. The doctor-patient relationship does not extend to validating the patient's belief that a problem exists. Because my bleeding was not cancer, Professor Trizz refused to see it as a problem. He dumped it in the wastepaper basket.

I get the impression that such doctors are inclined to believe that patients who present with wastepaper basket disorder are trash too.

Well before either Ativan or even The Horrors, I had a savage pain in my left cheek. Thinking it might be a sinus infection, I visited an EN&T bloke who washed my antrums using the holes left by another EN&T bloke twenty-five years earlier. He was gratified to be able to explain this phenomenon to the nurse. For me, he had nothing. He did not say, 'Have you tried aspirin? Aerobics? Prayer?' or 'Let's see who else might be able to help. . .' Nothing. Not anything. He'd done his bit and found wastepaper basket disorder.

But I, alone and unaided, nutted it out. In my salad days, when my fiancé introduced me to his friends, a dentist called Jack said portentously, 'You realise that this woman is dentally about eleven?' I was nineteen and my eyeteeth had not emerged. When I took the cheek pain to my elegant dentist, he X-rayed it and found the left eyetooth had grown horizontally across the jaw and was fouling a dense nerve bed. He cut the tooth out and the pain disappeared.

How nice it would be if doctors could admit ignorance and devise a contingency plan. 'I don't know, Mrs. Kerfoops. There's always the wastepaper basket - but how would you feel about an X-ray?'

While I was writing this book, I had a beautiful experience with my GP - who practises in a community health centre. I was chasing referred pain again and he said, 'I've forgotten where all those nerves come from. Do you mind holding on while I look it up?' And he reached for a little road map of the greater nerves and decided that yes, the pain could have been referred from my hip or spine and, since a manual examination did not discover any masses, we may as well forget it.

I cherish his plain good sense in looking it up. Lawyers habitually have basic libraries within easy reach. It would be good if doctors did the same. Medical information is expanding geometrically but the human brain is not. Doctors need to learn to use information storage and retrieval systems to save their poor strained heads. To say nothing of their poor ailing patients.

Benzodiazepine addicts find themselves trashed all the time. Indeed, one could argue that benzodiazepines are both the treatment of choice for wastepaper basket disorder and also its main cause.

The stress of coping with the medical system aggravates the patient's anxiety - which is also exacerbated by successions of new symptoms and new tests and the sheer physical stress of dragging oneself exhausted around the traps. This is obviously much worse for vulnerable groups: the old, the poor, the unemployed or the non-English-speaker - who may be vulnerable on all counts.

New problems arise before the old ones are resolved so that the patient does not know which one to pursue or is pursuing several at once. I put clumsiness and failing over to one side while I explored Stink and pelvic pain. Probably the iatragenic anxiety of BZD addiction and the reactive anxiety of dealing with an obdurate and insensitive medical profession leads doctors to think that anxiety is itself the problem and to ignore patients' other symptoms, even though they are quite distinct from anxiety. In fact, the patient is not simply anxious, s/he really has something to be anxious about.

Not all the misdiagnosed addicts are on benzodiazepines.

Veronica Paton dieted in order to be closer to the ideal shape for a ballerina: her diet pills brought her weight from sixty to forty-eight kilos but made her feel shaky, panicky, excitable, insomniac and paranoid. She had blackouts leading to the diagnosis of epilepsy and discussions of fitting a pacemaker to control her heartbeat. She was also, of course, addicted.<sup>1</sup> Cynical readers will note the irony that modem

medical science makes it possible to fit a pacemaker but not to diagnose amphetamine addiction.

#### **PAIN**

During the middle years of addiction, I suffered from a pain like a red hot cannonball stitched into my pelvis. It was hot, dragging and agonising. Sometimes it was so intense and so intractable that I could only lie down and sleep it off. Narelle went into hospital with a pain like this that resisted even the morphine she was given.

Survivors often ponder over their curious symptoms - why cobwebs and why on the end of the nose? Why worms and why in the fingers? Why a pain in the left side of the head but not the right? Why tinnitus in the right ear but not the left? I think that benzos may afflict areas already taxed by the common asymmetries of development and experience so that the excessive sensitivity called up by the drugs reveals areas stressed earlier in life, for example, by women's experience of childbirth.

I thought that if the pain was not gynaecological then it might be referred pain from my arthritic hip.

The rheumatologist was a man so handsome and well proportioned that he appeared to be relaxed and radiantly happy even when he was not smiling. His elastic gait, buoyantly waving hair and fine grained, lightly tanned skin gave an impression of health that passes for beauty even in a homely man. Clinic doctors almost invariably wear white coats. I'm a bit partial to men who wear their suits gracefully so I was glad to see that Dr. Genji was wearing a plain but elegant suit.

His suit underwrote the impression that I was facing a man who had such virtues and was so confident in his knowledge of them that he was, innocently arrogant.

He examined me and found all my joints working.

'Your yoga has served you well.'

Fair enough - I had been doing hatha yoga for fourteen years by then. Then he asked me to walk around.

'You have good legs.'

I took this to be a statement of fact. They are not good in the sense that men moan with delight at the thought of parting them, but anatomically good.

Alec said 'Good legs - you've got all your muscles.'

Gerald said 'Jesus! You've got legs like a ballet dancer!'

Billy said 'I know why you wear those crazy stockings - you've got good legs.'

The rheumatologist said 'You walk like a young boy.'

He examined me a second time on the couch - studied my firm and very white belly that has no stretch marks and asked my permission to peel my briefs back to the hairline where the scar of my sterilisation is barely visible. For a moment, he said nothing. Then he asked me to turn over.

Whereupon, he gentled my bum with a big, warm hand. And my bum spoke to my labia and my labia to my womb and my nipples and my lips.

'That was nice wasn't it?'

Of course it was! A splendidly handsome man, a large, warm, soft, strong hand that knows how to reach the id through the buttocks. I was as bitter as any cock-teased man but lying face-down on a high, narrow couch in a scarcely private space, I could not slap him.

'Oh yes! Very nice!' I cooed. 'You've missed your vocation. With hands like that, you should be an accoucheur - of the Lamaze persuasion, of course. I can just see you doing effleurage on birthing women. . .'

And thence to Le Boyer and thence to birth centres. By the time I was dressed and sitting in front of his desk he might have begun to suspect that I once wrote a booklet on natural childbirth. At any rate, he was beginning to look a trifle brown around the edges.

We never did come to taws over referred pain. There was so little human contact that I didn't even note the colour of his eyes. He might have been an android - a beautiful specimen but bereft of feelings. After the first unsolicited and inappropriate arousal, I felt no lasting animus but I had to consider the question, 'what if it had been some other woman? A non-English-speaking Turk? A veiled Anatolian?'

The complaints department of the mega-hospital was gratifyingly eager and efficient. I can't rule out the suspicion that the administrative staff were chuffed to have a doctor under the gun. But they had no sexual harassment literature tailored for doctors so I collected leaflets and posters directed to academics and sent some to the rheumatologist and some to the head of his clinic.

I didn't want to do more than that because I recognised him as the son of one of the early Women's Electoral Lobby women.

### **STINK**

After Dr. Dickhead tormented me over Stink, I went to another physician. There was a cubic metre of *Tatler and New Yorker* in his waiting room. It was not often disturbed. Most of his patients were on Workcare. A couple of fugitive, dog-eared *Women's Weeklys* circulated around the chairs stiffly placed against the walls. The bad-tempered receptionist hammered away on a manual typewriter. I could not remember when I had last heard one.

Dr. Dainty adjusted his shirt-cuffs to the appropriate degree of exposure from his jacket sleeve and invited me into his consulting room. I repeated my litany of excluded causes and disproven theories before undressing for a routine neurological examination. After I had put my fingertip on my nose, and followed his fingertip with my eyes, and stood on one leg patting the top of my head while describing circles on my stomach with my other hand and singing 'Eskimo Nell' backwards, he permitted me to get dressed and pronounced me well.

When I went down into Collins Street, I told myself that my brain was all right. If I'd had a brain tumour, he would surely have noticed something but his only discovery was that I am right-handed. I could not argue with that, yet I knew my brain was not all right and wondered how long it would be before my bane revealed itself.

His blood test replicated a previous test that showed a slight degree of anaemia. This could be easily accounted for by menorrhagia and indeed, Dr. Grace had said he thought it was. Nevertheless, Dr. Dainty insisted on doing an endoscopy.

Three nurses fluttered around the reception desk, each seeming to work from a different protocol. The waiting room was a large open space in which men in paper gowns circulated apathetically between flight-deck chairs very much like the failures in Frankenheimer's *Seconds.* Mercifully, I did not have to undress.

'How are your lungs? You don't smoke? No colds or anything?' asked the anaesthetist.

'I have asthma and bronchiectasis, and I'm a bit rattly just at present.' I said firmly, startled that Dr. Dainty had not told him.

'O Jesus! O shit!' said the anaesthetist. 'O shit! O Jesus!'

'Shut up!' said Dr. Dainty.

Still, they went ahead. The process is much less distressing than the bronchogram that diagnosed my bronchiectasis when I was thirteen and left me spitting for hours. When I refused a taxi because I wanted to walk across the park to a friend's house, Dr. Dainty pompously warned me that he would not be responsible for my welfare. All this fuss over a short walk, I thought, when he didn't bother to tell his offsider that I was a lunger!

The endoscope revealed only a slightly reddened stomach lining. Dr. Dainty wanted to pursue the putative bleeding further down the tract. He ordered stool tests and when one of those revealed traces of bleeding, he ordered a barium enema.

I began to think.

Given the variability of biological processes, and the great array of tests, it is inevitable that one or two results will turn up slightly on the positive side without meaning a great deal. It was quite obvious to me that Dr. Dainty was not looking for the source of Stink. He was just following his way through the available tests. I could have gone in with acne or a frozen shoulder and still found myself processed for months and months. If I didn't assert myself, I could be forced through every test on Medicare.

Dr. Dainty was quite shocked when I chided him with forgetting the purpose of our quest.

'I'm going for a job interview next week, and if I miss the job because I stink, I shall be very cross.'

I decided to accept an artery sonar using a newly arrived machine just to check the possible origins of the phenomenon labelled 'transient ischaemic attack'.

I followed the yellow line in the public hospital where, as a small child, I had followed the air-conditioning duct to an army portable where little asthmatics did physiotherapy on a splintery floor.

In the lift foyer, there was the usual trestle where devoted women sold crocheted toilet-roll covers and marmalade to raise money for the hospital. I left the lift to enter pink luxury. The paintwork was in myriad tones of pink. The armchairs were deep and upholstered in pink leather. The floral contract had obviously specified toning flowers. All it needed was a string quartet and I would have thought I was in *The Big Store*. The label on the wall told me that, although I had not left the building, I was now in a private hospital. It was quiet and not crowded - as befits a profit-making enterprise subsidised by the taxpayer.

The strikingly handsome young man who worked the machine was obviously proud of his skill. He made pleasant conversation except when he had to break off to address the computer and he understood how yukky it is to get jelly on your clothes.

I enjoyed the sonar. It did not reveal anything useful but I liked the strong beat of my heart magnified by the computer. My heart has always been my healthiest part.

The handsome technician said that the doctor to whom I had been referred only visited the hospital briefly in the evenings to check the tests recorded during the day. We did not need to meet. No bullshit about the doctor-patient relationship with Cnidian medicine!

Once all the results of my tests were in, I cut my losses and told Dr. Dainty to put his barium enema up his nostril.

### I NEVER WANTED A CRYSTAL BALL

I finished my MA while I was in hospital after the birth of my son then I started a PhD. I would take the baby to the University Creche and be outside the Library waiting for it to open. Then I would go inside, collect the necessary books and journals and go to sleep on the floor of my carrel.

After a couple of weeks, fearing that I would never get the thesis done, I went to Young Peter and asked for a referral to a psychiatrist. I had diagnosed writer's block. Young Peter never let me down.

'Up on the couch.'

Young Peter was a man of few words. After the usual listenings and tappings and 'say ninety-nines', he began to fill a syringe. I don't believe my memory - I see him holding a squat, clear bottle sealed with a red diaphragm held in place by a zinc ring - but that surely belongs to the very early days of penicillin?

'I raised an eyebrow.

'Pneumonia,' he said.

The next day, when he was sitting on the end of my bed with one ankle crossed over his knee, I asked what made him listen to my chest.

He paused while he retrieved a few words.

'Eliminate the obvious first,' he said.

If Rule One is 'do no harm', then 'eliminate the obvious first' should be at least Rule Two or Three.

I recall a story that I cannot authenticate, but which seems plausible, about a spinster secretary in a law firm who developed a nervous cough and great tiredness. For two years, a psychiatrist treated her for prolonged virginity derived from infantile sexual inhibitions. Eventually, lung cancer was diagnosed.

What happens when we apply Rule Two (or Three) to The Horrors?

From my earliest days, I knew two things about myself: my mother had died when I was born and I had a hollow chest. My stepmother's stories always started with the fact that my mother had been told not to marry, not to have a baby when she married, and not to carry the pregnancy to term when she conceived. The doctor wanted to terminate the birth but she was a Catholic and she said "Oh, we must

have our children!" This was one of many situations when I felt an implied criticism – 'and look at the result!'

I felt it again from Uncle Dave, whose repertoire included a setpiece of how he went out late at night with a prescription, woke up the chemist and saved my life. But the story always ended in silence - not even a cuddle. His effort had not been worth it.

My family had no investment in my life. They washed and fed me and sent me to school from duty and inertia. I was able to purge myself of that realisation in the company of Ellis Brown, a Perth psychologist who had devised a cathartic method of working through emotions that predated Arthur Janov's Primal Therapy. One day, after he had encouraged me to emote over some childhood insult, he said something over the top and out the window from what I had actually said. Nevertheless, it was true. 'They sure wanted you dead!'

Fossicking around in my early experiences did not a bit of good. I never received a single valuable insight from therapists. Their offerings were generally wrong, trivial, already known to me or readily available to introspection. Nor did they provoke me into insights of my own except insights about therapists. But Ellis's insight was something I would never have dared to produce myself.

However, I could produce insights like sweat whenever I read a fertile book. Bowlby's *Childcare and the Growth of Love*, Fromm's *Fear of Freedom* and *The Art of Loving*, Karen Homey's *Self Analysis*, Kinsey's *Sexual Behaviour in the Human Female*, *The Integrity of the Personality* by Antony Storr and *The Divided Self* by R. D. Laing, produced oodles of insights but insights have only a transient influence on feelings and little influence at all on conduct.

Eric Berne made a substantial difference. He says somewhere that patients suspect therapists of concealing in their drawer a crystal ball that could solve all problems if only they would share it. I never wanted a crystal ball but I did believe that therapists should have something like a slide rule that they could teach me to use. The other books were analgesic, they validated my past experiences but did not give me any handle on the present. Transactional Analysis is based on closely observed conduct, and concerned with dealings between people in the here and now rather than the forever receding childhood. It was the tool I wanted.<sup>2</sup>

But Berme did have one blind spot - and he knew it. He really had no answer for strongly felt emotions except to talk them under control. But there is an ontological pain that cannot be talked down. I was born with it - the legacy, perhaps, of my carriage in the womb of a woman who knew she was likely to die of her pregnancy. And did.

The pain was my integument, unnoticed much of the time but always available to notice. It was with me for 50 years. I passed my life like the Little Mermaid pretending to be human, my feet hurting at every step.

Any psychiatrist who looked at my childhood could be confident that s/he had a rich seam for neurosis, zero self-esteem, masochism or any other disorder. But, if s/he had followed Young Peter's rule, s/he must have noticed that, although I was not a malingerer, I was unable to get lasting relief from talking therapy. S/he would have asked why my distress was intractable and what about my family history.

Some time around my fortieth birthday, I used to joke that I could not remember whether I had seen twenty therapists in sixteen years or sixteen therapists in twenty years. This is perhaps not so frivolous as it sounds - some of them only rated one visit. In any case, none of them inquired about my heredity.

My father's sister had Korsakov's syndrome several years before she died of alcoholic kidney failure. She had been drinking for thirty years. Her husband died of a massive stroke consequent on alcoholism. My elder uncle was a hopeless lush who found himself a berth as a steward at the Melbourne Club where he could safely tipple. As an eight-year old, I made one of my rare spontaneous gaffes when I asked a family gathering whether anyone had ever seen Uncle Tommy sober.

My father's middle brother, my Uncle David, was a heavy smoker whose binge drinking was somewhat moderated by gout. He suffered from periodic bouts of depression where he kept to his room except for meals, emerging half-dressed and aggressively miserable. At other times he was splendidly expansive, hail-fellow-well-met and given to foolishly sanguine risks.

I cannot say how long these cycles were, but I know they were cycles. At the time, I thought it was his gout that slowed him down.

Freda alias Freddy, Skinny, and Birdie, who refused to marry my father because they were first cousins, was still drinking Bailey's Irish

Cream when her fingers and toes were mummified with the gangrene of gerontic malnutrition.

My silent, dignified, upright father, who supported these casualties one way and another all his life, never abused alcohol but he was never relaxed and laughing unless he had been drinking. A thread of alcoholism, domestic violence, reclusiveness, religious mania and suicide may be picked up elsewhere in my father's family - possibly as far back as the seventeenth century.

My mother's family had a high degree of eccentricity. One of my earliest puzzles was seeing one of her brothers, a bank manager, which still meant something in 1949, prosperous and beautifully dressed, on the tram, biting his nails and talking like a married magpie - to himself.

Despite their various closeted skeletons, all the branches of my family were eminently respectable and suburban. They were also very enclosed, strongly bonded to each other and very conservative about these bonds.

I had had The Horrors for about a year when I read Fieve's *Moodswing.*<sup>3</sup> I did not immediately see its relevance for myself but I could see members of my family throughout the book.

Pondering all the evidence as I packed for London in 1978, I came to the conclusion that I came from a family with a well-controlled potential for manic-depression that had never come out in me because whenever I pushed things too far in any direction, I went into status asthmaticus or pneumonia and bedrest prevented me from going any further. Nuelin/theophylline had probably elicited a fast-cycling version of the condition in me. That's my theory - but no doctor has ever confirmed it.

It would have been reasonable for any doctor looking at my history to consider a cyclic mood disorder and to make a trial on lithium - it would have ruled out the obvious.

From August 1978 to about February 1980, I lived on alternate days unless commitments to others forced me to stay out of bed. I saw a great deal of England and Europe and I published *Women, Sex and Pornography*.

At one point, the anguish became too exhausting so I told my story to a psychiatrist who was working with lithium at the Royal Free

Hospital. He agreed that I sounded a likely prospect for the treatment but could not accept me into his research programme because I would be returning to Australia before it was finished. However, he referred me to Professor Guppy who referred me to someone in his department.

### THE HORRORS

He walked as though his arse chewed minties. He was slight, and about average height, and he carried the smaller version of the Italian shoulder bag that I had bought to replace the German buffalo hide sac that was stolen from me at knife-point in Hampstead. I never got around to asking him if he had picked his bag up at the Harrods' sale. His room was desecrated with trivial kitsch: an Aztec calendar figure put together with a lurid raffia made from petrochemicals, a polymer version of Botticelli's Venus, a copper relief of Windsor Castle - I forget the rest.

Dr. Minty said that lithium was for people who are all right ten months of the year and can't get out of bed in the eleventh. I could not persuade him that not being able to get out of bed every second day is also a liability.

By the late 1980s, when theophylline was no longer a popular drug, my story elicited responses like:

'It's a dreadful drug - should never be used!'

'It's a very harsh drug - I never use it.'

'It's a bad drug - needs to be carefully monitored.'

'It is common knowledge that it causes a variety of unpleasant side effects.'

'Sure it will cause The Horrors - and so will some of the other asthma drugs!'

But in 1977, when I first reported to the thoracic clinic that I was taking amitriptyline and Valium for what I believed to be side effects of theophylline, Dr. Shy guffawed and said 'Ho! it gives you the shakes, does it?' I felt then that this was uncouth and unhelpful. I think now that the poor man was probably embarrassed and did not know what to do.

Certainly the two entries in my mega-hospital file around this time are quite respectful of the problem - they are both marked 'NB ... !!' But Dr. Shy did not suggest I discontinue it.

Neither did Dr. Minty, although he was well aware of the nervous effects of asthma drugs. Indeed, when I said that I was getting a rush out of using the Ventolin nebuliser when I was asthmatic and tired, he became quite stroppy and said he was going to speak to Fred Scratch. If he did, Dr. Scratch did not tell me. When I mentioned that I was receiving Ativan from Dr. Minty, he merely sighed and smiled insincerely and said 'O … We all know Fred Minty!'

Just as I had been divided up between the O & G man and the thoracic bods when I was in labour,<sup>4</sup> I was now divided up between the thoracic bods and the psychiatrist. Both experiences were bad for my health catastrophic, in fact.

These divisions are essential to the demarcation of the human body into areas of specialisation for the purposes of providing consultants with higher incomes than GPs. They make nonsense of the concept 'doctor-patient relationship.' The alleged doctor-patient relationship is always secondary to the doctor-doctor relationship over the body of the dismembered patient.

Dr. Minty offered autohypnosis to replace the Transcendental Meditation that no longer worked (and, indeed, has never recovered). The tape had no effect at all. I found his flat voice and genteel Australian accent a goad. After several months, I declared the technique a failure and was offered biofeedback.

The woman who wired me up to the machine was so tense, speedy, and flighty that I asked myself how anyone could justify bringing her in contact with patients. Before the rebirth of feminism, one would have said 'All she needs is a good fuck' and still been aware that fucking would not do it.

I had many highly successful sessions where I relaxed at will and turned off the buzzer. And each time she recorded a successful session, I would say 'Today is a good day. Wait till you see me on a bad day.' I had no way of knowing whether she had heard me. Eventually, tired of suffering, I asked her when we would get around to generalising the effect of the machine. She did not know what I meant.

'Well, it's fine on good days when I don't need it but I want to be able to relax on bad days.'

Eventually, by coincidence or the law of averages I had an appointment on a bad day. Suddenly she understood. She disappeared without a word, reappearing with Dr. Minty. Standing at the door of her room, and without consulting me, he wrote a prescription for Ativan.

It subdued the day-on, day-off horrors for almost exactly three years. When they returned, I was well into addiction and my marriage was breaking up. During intoxication and withdrawal, the alternate better day became a crutch that helped me crawl forward.

In 1988, finding that the effort of getting through the bad days and disguising my condition at work was leaving me exhausted for the good days, I went to Dr. Blank in a fresh search for lithium.

I include 'Castel San Angelo', a detailed record of that interview, because it illustrates how withdrawal effects the fine details of social contact but I wrote it for a vastly different reason.

BZD disorganises the sexual response, influencing different parts of the four-stage cycle at different times. Initially it intervenes between arousal and climax, making climax much harder to reach. Withdrawal can create intense and very distressing arousal. I have very little data on BZD and sex from the support group. I felt like a pig in a minefield a lot of the time so if people did not volunteer information, I did not ask for it.

Okame badgered her lover for sex until he began to use nasty, obsolete words like 'nymphomaniac'. Nina went pub-crawling and was ashamed.

With me, it acted like a love philtre for any man I met in the months that the effect lasted: my lunatic self would fall in love while my monitoring self told me not to be ridiculous - the man was an ass's head, a cane toad, gay or married.

These crushes were never expressed. While I was still legally married but living in a set-up called 'separation under one roof, I had decided that I was in no condition to be taking risks on new love affairs but that I could safely respond to lovers who had mellowed into friends - men I had known for five, ten, nineteen or twenty-one years would be unlikely to take advantage of my vulnerability.

'That little house isn't doing you any good,' you say. 'Why don't you come to me for the weekend and get some sea air?'

We stand on a thirty thousand-year-old midden of oyster-shells, watching a delicate Canaletto sunset.

You are like a familiar book, always available on its shelf, always fascinating but somehow never read. I ask myself whether you are, at heart, a sadist who is taking me for a masochist? Do you want to exploit my competence to further your reputation in the art world? Have you invited me just now because your girlfriend had run away with a cavalry officer, slim, elegant and dressed in astrakhan?

Yes. Yes. And no.

(He turns out to be a good-looking Syrian terrorist speaking French like a native. She is lucky not to end up with a bun in the oven and a bomb in her dilly bag.)

You like your food so you have been forced to learn to cook and you cook something simple and exquisite - trout, snowpeas, potatoes with pink skins. We listen to Mahler and I slide away from every hint of seduction like a chaste eel. Eventually, you peel a mandarin and feed it to me in segments.

'What are you frightened of?' you say, wondering.

'Nothin' I say truthfully, having every reason to trust you. 'Everything' because that's how it is in 2.5mg addiction.

You take me by the shoulders and steer me into the master bedroom. You sleep in the guestroom.

I fell in love with Dr. Blank and wrote 'Castel San Angelo' to earth the urgency of my desire and my bitterness at his ignorance of BZD.

He did not treat my request for referral expeditiously and I was terribly conflicted about going back to Professor Guppy. I suffered greatly over the weekend and rang the hospital on Monday morning to see just where the referral was in the pipeline. Nurse Rached said they would post it soon. We were then in the middle of a postal strike.

Closer to suicide than I had ever been, I telephoned Piers.

I never ask my doctor friends for medical help unless I am in extremis - it complicates friendship so. I was in extremism

'Can you hold out until five o'clock?' he asked. 'I've got a free spot then.'

Somehow, I muddled through the day and was laughing when I turned up at his lovely Victorian house with its splendid rose garden, slap in the middle of an industrial back street, facing a row of silos. I stumbled through the long story in a short time.

'Well,' said Piers when I had finished, 'you really have earned your trial on lithium.' And he added, 'You've had a dreadful time, and I don't

want to make it any worse for you. I want you to have a few tests to make sure that it's okay for you to have lithium.'

It was. Piers started me on a low dose (400mg nightly) that stopped the cycles but left me feeling too slowed down to think creatively. At 300mg, the cycles are faded to a tolerable level -reducing the difference between happiness and anguish to the difference between optimism and pessimism, and I can write as fluently as ever but with more effort. Whenever I have dropped to 200mg, the bad days are too bad to bear.

### LITHIUM MONITORING

Lithium, a naturally occurring substance, has a fairly narrow window between the amount needed to do you good and the amount that will cause unwanted effects, so the dose needs to be adjusted to the individual patient and then checked every so often to make sure blood levels remain within the therapeutic range. The unwanted effects range from diarrhoea and headache to kidney damage and death.

Not long after Piers got me settled on lithium, he went overseas for his usual musicologist's Northern Hemisphere binge. To save time, I asked Dr. Muffin, the GP at my work to monitor my blood levels. He agreed but let Dr. Hearty persuade him that only a psychiatrist can do it.

It was a psychiatrist who sent Shelley overseas with five hundred tablets each of lithium and Valium in plastic bags. Fortunately, she was in a developed country when the blinding headaches overtook her. Emergency hospitalisation prevented the lithium overdose proceeding to serious kidney damage.

Psychiatrists are no more reliable than other doctors when it comes to drugs.

Dr. Minty was a teaching doctor in a prestigious university medical school attached to the mega-hospital where I was an outpatient in the thoracic clinic. Nevertheless he put me on Ativan and told me I would be on it for the rest of my life despite the fact that two years earlier, the Committee on the Review of Medicines of the British Medical Association had recommended that BZD be prescribed only for short-term use and never for depressives or patients with chronic pulmonary insufficiency.<sup>4</sup>

The skill in lithium monitoring rests mostly with the staff at the pathology service who draw the blood, test it, and relate it to their own

scale of tolerance. If the service advises that levels are over the limit deemed safe, the doctor then advises the patient to drop a few tablets. With a manic psychotic on a high dose, s/he will need a certain degree of experience and judgement to gauge the right drop but for a competent individual on a low dose, a GP, a nurse or, indeed, the patient alone can safely titrate the amount.

Ever conscientious and foresightful, Piers had given me the names of two doctors who could supervise my blood levels and watch my progress. Dr. Dildo and Dr. Kildare happened to be psychiatrists and each of them made a terrible welter of a very simple request.

Things hadn't improved in the ten years since Barbara Gordon published her Valium odyssey. Coming off cold turkey from thirty milligrams a day for about ten years, she was twice hospitalised during withdrawal and saw additional psychiatrists in between. Only a psychologist in a therapeutic community explored the effects of withdrawal, and then only superficially.

The rest persisted in identifying other conditions for which she needed treatment - including one psychiatrist who called her depressed, anxious, phobic and severely neurotic. At that time, he was withdrawing another patient at the rate of five milligrams per week. Ms. Gordon was also labelled schizophrenic, cyclothymic personality, borderline psychotic, manic-depressive, agitated depressive, hysterical and female - everything except 'benzodiazepine survivor'.

My first six years of school had been a Sartrean hell of boredom where every year, history started with the dinosaurs and got as far as the Civil War before it was time to change classes. Like an Anabaptist praying for the Second Coming, I hoped for the day that we were told what happened when sexy King Charles was restored.

Most - I may as well say 'all' - of the psychiatrists I have dealt with started with the dinosaurs and spent so much time on the archaeological dig that I solved my own problems in the meantime. Instead of simply accepting the referral to monitor my lithium, both doctors insisted on getting a detailed history, not merely of my BZD addiction and withdrawal but of my marriage and the whole of my previous life. They were trawling for custom. I was too tired to prove my stability by complying with unreasonable doctors for a reasonable trial period.

Never close one option until you know where you are going. I telephoned Dr. Manners.

'You remember you said that psychiatrists are useless? Underwater macramé? Not worth a knob of goat-shit?'

'What I precisely said was underwater cake decoration! Not worth a pinch of cocky-shit!'

'You know,' he had said regretfully, in a tone of gentle warning, 'the psychiatrists are not very good ... You know how many brain surgeons we'll graduate this year? One - if he's good enough! Anyone can be a psychiatrist who wants!'

And studies of medical school class lists do show that psychiatrists come from the bottom. It may be that students who do not do brilliantly under the existing system of Cnidian medical education are those whose personalities are ideally suited for healing fragile psyches. The alternative is that psychiatrists are a mediocre group driven by ambition for the income and status that specialisation brings with no particular interest in the only specialisation open to their limited capacity.

'Well, you won't be surprised to find I've had another dud ... ? And you are quite competent to supervise lithium, aren't you?'

Of course he wasn't. And of course he was. Safe in his promise to help, I cancelled my next appointment with Dr. Kildare. I nursed Dr. Manners's last words like a hot pack: 'What do you want lithium for when you function so well?'

### THE ECOLOGY OF HELPING

Iatragenic drug addiction is more a problem of general practice than of psychiatry - but psychiatry has a significant ecological influence on the use of psychotropic drugs in general practice. It is not generally recognised that psychotherapy is the disaster area of the medical profession, claiming territory from general practitioners and disempowering them from devising more effective responses than pills to conditions involving any factor that can be construed as mental.

The existence of a specialisation that allegedly caters for environmental and software problems permits Cnidians to define them

as off-limits. Since the GP lacks the time or the expertise for the imputed therapy, s/he is encouraged to diagnose wastepaper basket disorder and substitute a psychotropic quick-fix-barbiturates, meprobomate, benzodiazepines and, now that the latter group is being discredited, tricyclic antidepressants.<sup>8</sup>

'I think one of the problems GP's have at the moment is that they feel they either don't have adequate alternatives, or that they are unskilled in delivering them,' said Associate Professor Larry Evans. 'The reality is that many of the alternatives can be delivered by GP's and they are very good at it.'9

Psychiatry arrogates the psyche to its own territory and general practice defers to psychiatry without realising how ineffectual most therapies are. Psychiatrists are medically qualified and legally able to prescribe drugs; psychotherapists may or may not be medically qualified but they prefer to heal by talking; psychoanalysis is the form of talking therapy devised by Freud, requiring several hours' therapy per week for several years - or many. Woody Allen has been in analysis most of his life.

Between 1959 and 1980, the number of purportedly different therapies practised in the USA increased from thirty-six to well over two hundred and fifty. The vast majority of psychiatrists and many other therapists acknowledge Freudian influence. A sample of individual, case histories from significant practitioners does reveal differences in approach but large-scale research shows that results do not differ from one method to another. 12

Whether psychiatrists cure is problematic and so is how they cure and even what they are curing. The terms 'neurotic', 'psychotic', 'mentally ill', are not so much diagnostic as labels that cue doctors and nurses how to treat the wearers.

Once labelled, even inarguably normal agents will be treated as abnormal. Eight pseudo-patients, including a psychiatrist and a professor of psychology and law, gained admission to twelve hospitals in five different American states. Their presenting symptom was that they heard voices but they behaved normally. Remaining in hospital for between seven and fifty-two days, they were barely observed by the staff - although they recorded their own observations carefully.

None of the staff detected their imposture but the genuine patients often identified the pseudo-patients as journalists, researchers, or auditors.<sup>13</sup>

When this research was published, the most common response from the therapeutic establishment was not soul-searching or breastbeating or even critical reflection. It was the claim that the research was unsporting.

Speaking as a participant observer of over thirty therapists, ranging from psychiatrists, through psychoanalysts and eclectic therapists to oopsy woopsy human potentialists, the main discernible difference is not between differently qualified practitioners, or between the ideology they espouse, but between men and women.

My brushes with psychiatrists illustrate two points that have been implied several times in this discussion.

Firstly, in the doctor-patient relationship, the patient is often a conduit for piping tax dollars around the medical-industrial complex: as part of the complex, doctors also pump tax dollars to the drug companies. I suspect - but have no hard evidence to prove - that those doctors mostly likely to invoke the doctor-patient relationship are those most likely to diagnose indications for Private Insurance Caesarian and Private Insurance Endoscopy. At any rate, whenever I hear anyone invoke the doctor-patient relationship, I know s/he is defending self-interest.

Those doctors who make snide remarks about Mediterranean Back and RSI should consider the statistics demonstrating that private insurance is a lowering condition that predisposes patients to develop just about anything but most often the diseases of the rich.

Of course, a good few doctors - mostly Coans - are concerned about their patients and their price is above rubies. Rubies are scarce too.

Secondly, iatragenic addiction derives largely from the failure to discriminate between hardware and software. Although I had been referred to Dr. Dildo for lithium supervision (hardware), he had wantonly ignored my blood levels to tinker with my emotions (software). Without addressing the problem of monitoring lithium levels every couple of months, and after a careful exploration of my finances, he concluded that what I needed was twelve months' group

therapy with him on a weekly basis. Perhaps he had diagnosed that I could not afford his purple suede couch several times a week and he could not afford to check my lithium several times a year.

That exercise about the raft was badly set up. There have been protocols for such situations since the days of sail: drawing lots, triage, self-sacrifice. But it was conceived around a fallacy - that some individuals are more worth saving than others by virtue of their roles. I do not say that roles are meaningless: I rarely swear in front of a nun and I usually manage to be polite to professors and retired judges.

But, in the end, the role is superficial; what matters is how it is filled. A good many of the doctors in my story have been content to assume the role of doctor while forgetting what it is that doctors do. Good doctors, Coan doctors, do not play a role for the approval of their peers or to establish an affluent lifestyle. They look to their patients, to heal them or, if that is impossible, to help them bear their suffering.

### THE CREMASTERIC REFLEX

Oliver Sacks, a neurologist internationally famed for his medical writings as well as his professional acumen, tore his quadriceps while running from a bull. After the muscle had been surgically repaired, and the leg sprinted, he found himself unable to make it respond for physiotherapy and, indeed, the leg seemed to have lost its reality for him. 'Part of my body-image, my body-ego,' he writes, 'had died a frigid death.' He consoled himself by looking forward to a frank talk with the Surgeon.

When the Surgeon came, followed by the Senior Registrar followed by his juniors, and a trailing group of students, Sacks presented his problem. The leg was fine, but he could not contract his muscles or feel it.

'Nonsense, Sacks,' he was told. 'There's nothing the matter. Nothing at all. Nothing to be worried about. Nothing at all!' ('There is nothing there, Mrs. Kerfoops - nothing at all!) Silencing his patient's protests, the Surgeon left. The scene was replayed when Dr. Sacks asked for an interview with the Registrar. Much later, the leg was found to be profoundly denervated.<sup>15</sup>

If you are tempted to discount my anecdotes, remember Oliver Sacks. There is something in the way doctors construe their role that

precludes communication between them and their patients - even when the patient is another, and very eminent, doctor.

No doubt some reader will ask whether I, being me, did something to bring this mistreatment on myself. Remembering Oliver Sacks, I am inclined to say 'no'. Remembering that all communication is two-way, I am willing to concede 'possibly'.

'Remember, my love,' said Jason, who was fifty when I was twentyone, 'that whenever a man argues with a woman, he argues with one hand on his balls!'

Men commonly accuse women of wanting to castrate them. Dr. Jean Lenane, aware that she had never had any such impulse, quizzed other women.

'They often wanted to push a man over a cliff, but never to castrate him,' she said.  $^{16}$ 

Pondering this anomaly, Dr. Lenane concluded that men misinterpret women because they respond to a message from their own bodies. The cremasteric reflex, as every footballer knows, tightens the scrotum and pulls the testicles closer to the body when danger threatens. It is a Darwinian survival mechanism, quite useful so long as ships were made of wood and men were made of steel but increasingly maladaptive once ships were made of steel and the Industrial Revolution began to select for a different type of man.

Men who feel threatened blame women for threatening them (just as men who feel randy blame women for arousing them). Men do not seem to have a clear idea of where their feelings are coming from.

The castration myth is simply a failure of communication between the man and the woman derived from an earlier misunderstanding between the man and his balls. The cremasteric reflex can result in irrational prescribing when it arcs during a consultation.

One day, when I was wearing one of my favourite outfits, I turned on the blender to make a quick breakfast and sprayed a fine wool dress and suede shoes with Adele Davis's health drink. I was angry with my son for not screwing the blender tightly when he put it together; angry with my husband for not understanding how I felt; angry with fate for sending this disaster when I was in a hurry to get to the eight-thirty thoracic clinic.

I was still angry when I arrived. I romped through a consultation with Dr. Male. When he had repeated my usual prescriptions, he said 'You're depressed. You'd better have an antidepressant.'

Think about the body language and feeling of depression . . . Think about the body language and feeling of anger - even of carefully suppressed anger . . .

Dr. Male was certainly confusing these clearly defined and contrasting states but there was more to it than that. He was confusing the bad feelings he experienced in my alert, upright, seething presence and the source of those feelings. Instead of controlling his scrotum, he wanted to control me.

From the earliest days of second-wave feminism, women have been accumulating information about how women and men communicate with each other. Deborah Tannen has begun the task of clarifying the social implications of this. Men use report language, communicating information. Women use rapport language, establishing consensus. Men confront, women collaborate. Men argue, women discuss. Men preen, women groom. Men indulge in jockstrapping to impress either women (epigamic display) or men (epidiectic display) - and jockstrapping is essentially deceitful.

The discrepancy between the two communication styles encourages women to see men as dominating and men to see women as feather brains. Both views are partly right and partly wrong.

Communication takes on peculiar importance when the matter to be discussed is health. Doctors who make decisions on behalf of patients often assume that they know what the patient's values are and usually don't.<sup>19</sup>

Sex constitutes a subcultural division as much as ethnicity and socioeconomic status. Women are generally so badly served by male supremacist medicine that they are voting with their feet, establishing women's health clinics, patronising community medical centres and looking for female doctors. Many male doctors in mixed practices cannot understand why their female colleagues are so popular.

Let me show you an example of failed communication.

Although my condition has been stable over many years, it varies enormously from day to day. I use a simple peak flow meter to monitor

the workings of my lungs - particularly before and after Ventolin. My after therapy improvement ranges from -20 (yes, that does mean I can be worse after Ventolin) to +90, with an average peak flow of about 175.

But the interesting fact is that the readings do not fluctuate only or even mainly according to whether or not I have an infection but according to how long it is since I woke up and whether I am relaxed, rushed, depressed or frazzled.

I tried to initiate a discussion of this with an intelligent, socially aware and decent consultant by saying that I thought my trouble was mainly cerebral. He reacted with such a violent moue of disgust that I would have had to deal with his anger before I dealt with my query and my stamina was not up to it.

Here's how Dr. Decent could have handled it. First, he might have articulated his annoyance at my apparently stupid comment.

'As you can see, I find that pretty hard to take. You've had bronchiectasis and asthma for fifty years.'

Then, he might have tried to find out what I meant. 'What makes you say such a loopy thing?'

I speakto him ... he listens. He speaks to me ... I listen. I speak to him . . . And lo, we are having a conversation. He learns that orgasm and TM are often as good as Ventolin and Ventolin is often no use at all.

I must say the women doctors in my long experience were more kind and less hurtful than the men. Here is a woman doctor at work.

Beset by clumsiness, blurred vision, extreme tiredness, loss of appetite, and loss of weight, I did what many BZD addicts do - had an AIDS test. Just in case a sexually transmitted nasty had survived the antibiotic soup that often flowed in my blood, I was also tested for syphilis, gonorrhoea and the rest.

I went to the women's STD clinic near my work - it was convenient and, having once cased a government clinic to write articles for *Nation Review*, I was interested to see what had changed in fifteen years.

'You have had a rough trot!' said the doctor when she had finished noting down my medical history. *Sympathy*.

We went through the ritual of sexual partners, using their given names. She asked 'And did you do oral sex for Tom? For Dick? For Harry.'

My face must have managed to express curiosity for Dr. Kind explained the rationale without my ever asking for it. *Intuition. Sensitivity.* 

'Girls don't like you to think they are promiscuous so we don't use numbers-always names. It is more intimate and friendly. And we make it sound altruistic - they like to pretend they're doing things for the men, not because they enjoy it themselves. Then we can be more sure we're getting the truth.' Self revelation. Sharing trade secrets.

After that, Dr. Kind gave me a running commentary on various aspects of the protocol. *Treating the patient like an adult.* 

Her touch, when she took the oral, vaginal and rectal swabs was quick, deft, light and unobtrusive. Consideration for the patient's physical comfort and modesty. I've had genital examinations from three female doctors and they all had that delicacy. I cannot compute how many male doctors have examined me but I have only found one man with this touch.

Of course, I did not have AIDS or any other STD but Dr. Kind did not waste-basket my symptoms - she suggested that I see a general physician. Sustained concern for the patient.

The experience left me feeling that I had encountered a healer - a bright light in a naughty world. I could have been a prostitute or a professor but, to her, I was first of all, a patient.

Report language can work very well for straightforward problems. When flu swept through my department, I was the last person available to go to a conference. Of course, I took the flu with me. On the second day in the country town, I had to chase antibiotics against my regular bacterial infection, which was worsening.

The clinic waiting room was an ingenious use of space: the wall that usually opens onto the alley down the side of a house had been converted to a picture window and the alley filled with greenery like a winter garden. The patients sat looking into this magical space.

Dr. Magic, when I first saw him, was striding along a corridor with his stethoscope around his neck like a busy man. I liked that. When I was finally called into his room, the first thing he noticed was the nametag I'd forgotten under my coat.

'What is a Mac Fax Duct?' he said.

'A way of communicating by computer.'

'And you're not communicating very well!'

I quickly ran through the history of my lungs and got to the present infection.

'The peak flow meter shows I'm not responding to Ventolin.' 'It's not getting in. The tubes are blocked.'

'I've had a course of Vibramycin and a course of Mysteclin and my sputum's still dense and green.'

'You must have a bug that's too big for them. You're staying at the motel?' *Translation – 'You can't go to bed?'* 

When I assented, Dr. Magic had a quick listen and wrote out a prescription. *Ciprofloxacin*.

Notice the simple exchanges of information, each one leading the consultation a step further towards diagnosis, prescription and closure. No dithering and no jockstrapping. He was good at his job and was not at all threatened by the possibility that I might be good at mine.

After the conference, I had a couple of days in bed, watching the antibiotic do its work. The doctor was probably bending the guidelines in giving me ciprofloxacin without a culture to determine exactly what bug I had. But it was a reasonable risk - I had had pseudomonas twice, I could not go to bed immediately, I had tried other things that failed and I was getting worse.

Dr. Magic had successfully matched pill to ill.

Some doctors are adept in both report and rapport modes. When I was chasing Stink, I went to a small clinic in Fitzroy, cheaply furnished but smart with paint, and plants and posters. It could have been a unisex hairdresser's shop or travel agency. The doctor looked like one

of those eternally youthful, graceful Englishmen who turn up in *Brideshead Revisited* and *Empire of the Sun,* fresh, and clean, and brave and vulnerable.

Dr. Grace took my problem seriously, looked at my teeth, inquired after my digestion, prodded my liver, listened to my lungs, and considered my medications. And with every exchange of fact, there was also an exchange of sympathy, of concern, of kindness that was not so much expressed in words as in tones of voice, and eye contact, and gentle hands.

A blood test revealed trivial anaemia, probably related to menorrhagia and too trivial to explain my intense tiredness. There was a moment when we looked at each other and he reflected on the word 'tiredness'. It had no connotation of malingering for him. It was a valid symptom of something he could not diagnose.

When he could no longer think of alternatives, he sighed and wrote out a referral to a physician.

Dr. Grace sighed because tiredness has special saliency in his practice. He is, in fact, a venerologist, and gay. He was working in general practice so that men at risk of HIV would feel able to seek help without the stigma of going to an STD clinic or a consultancy. He needed occasional women and children to keep up the front of normalcy.

Yet I did not feel like a token female. Unlike Professor Trizz, Dr. Grace's healing art was available to all his patients - not just his special interest group. I was not male, gay or HIV positive but I was, even briefly, his patient.

# CHAPTER 12 DON'T SAY YOU ARE SORRY! SAY YOU WON'T DO IT AGAIN!

I wouldn't try to hang the last doctor with the guts of the last detailer-these utopian solutions never work!

Maximillienne

#### A SURFEIT OF OPTIMISM

'The benzodiazepines have been static for a decade now,' Professor D. J. Birkett told the House of Representatives Inquiry into the Prescription and Supply of Drugs in 1992. 'I could regard that as a triumph, in a way ... we have a wonderful mechanism for achieving things in Australia.' Wonderful mechanism...? For the first half of that decade, I was succumbing to benzo sickness; for the second half I was struggling out.

How many people are still there? We do not know the exact numbers but in 1990, 10.6 million BZD prescriptions were issued to 750,000 Australians.<sup>2</sup> As a general rule, once the increase in prescriptions stops, the continued prescriptions are to maintain patients already addicted. TRANX told the House Inquiry that its work is increasing.<sup>3</sup>

In July 1992, the Federal Minister for Health reported that as many as 40,000 people per year are admitted to hospital with adverse reactions to prescribed drugs and 700 to 1,400 people die of adverse drug reactions. The problem of iatragenic illness, extending well beyond BZD, costs the Australian community about \$69 million annually. In Britain, the corresponding figures are 47,000 admitted to hospital with 2,500 deaths. In the classic cycle of private profit and public harm, the pharmaceutical industry posts dividends while government posts losses and voluntary agencies aid the survivors.

The AMA responded that Australia's difficulty is not large considering that 440,000 prescriptions are written daily and that the issue itself was a Labor Government beat-up to camouflage the problems in Medicare.<sup>5</sup> This reply failed to acknowledge that each year at least 700 families have cause for grief and for grievance, that no fewer than 40,000 people go to hospital, and that \$69 million is spent gratuitously. Most of the contributors to the House Inquiry said that the

rate of prescribing is itself part of the problem and that Australia is, in most drug areas, a vastly overmedicated community.

Australian doctors prescribe more than twice as many antibiotics per head of population, as Swedish doctors do.<sup>6</sup> Moreover, numerous consumer groups complain that doctors are poor communicators and that existing services are unsatisfactory.<sup>7</sup> The rise of the women's health movement and of alternative medical traditions are a clear index of popular dissatisfaction with Cnidian medicine.

Braithwaite is obviously right in saying that the adversarial system of regulating the pharmaceutical industry does not achieve the protection the community must have. Although there is a plausible argument for reintegrative shaming of white-collar criminals in the drug industry, shaming will not work for the doctors' wing of the medical-industrial complex.

The AMA is clearly not shamed by hundreds of ADR deaths and \$69 million worth of illness. Many doctors are immune to shame, not only because their profession is so adroit at closing ranks but also because most of them do not see themselves as calculated wrongdoers. According to Dr. Barbara Booth, Director of Quality Assurance, Royal Australian College of General Practitioners, there are very few bad apples. There are, however, lots of Cnidians.

Doctors generally are not psychopathic, irresponsible or lacking in a civic sense but they are often handicapped by their training - like those American pilots in Vietnam who, having been trained to fly on instruments, bombed their own troops. Shaming will not turn Cnidian doctors into Coans - reformed education might - but education is a long-term strategy. Doctors are reluctant students.

The South Australian 'Women and Minor Tranquillisers Campaign' did not gain the active participation of doctors.

Despite our zealous efforts not to blame the medical profession, we suffered the full force of doctor's [sic] defensiveness. Despite our attempts to involve doctors and to acknowledge the complexity of the problems they face, we did not have the support and co-operation we had hoped for. This also reflected the 'private practice' nature of their work and their inherent difficulties in becoming involved with two-day workshops and meetings. In some instances, it involved their reluctance to debate the issues with other health and welfare workers who had little or no medical training. Our expectations for change in this area were too high. A gradual and subtle input into medical training will in the end have greater input.<sup>9</sup>

Diana Dutton's caveat on health scandals is a useful lead-in to the medical side of the complex. She distinguishes errors in the way decisions are made from those caused by the state of available information. By now you know that in most rogue drug scandals, relevant information has been available very early in the product life cycle. These tragedies arise less from lack of information than from a surfeit of optimism.

The US swine flu campaign, which reveals failures deriving from persistent overoptimism at almost every stage, is a warning example. The initial prediction was pessimistic: a tiny, localised outbreak of a mild variety of flu led to excited predictions of another Spanish Flu epidemic that was expected to be widespread and lethal.

Very few scientists accepted this gloomy prediction but lack of public scrutiny meant that those who did could avoid debate by indulging in denial of criticism. President Ford also expected to gain from funding a campaign against the menace of a widespread and lethal epidmeic. Once the relevant agencies were persuaded to accept the worst prediction, each subsequent stage was unrealistically sanguine. Worst-case thinking, Dutton concluded, 'rather than best-case, might have helped ferret out many of the lurking problems in advance . . .'12

# **WHOSE RISK?**

Neither attitudes to risk nor the subtle problems of assessing risk will be solved simply by making information available. 'What is not made clear in the drive to legitimise risks, however, is exactly *who* will bear *what* risks. And with good reason,' observes Dutton. 'For while it is private industry that benefits most directly from a relaxation of safeguards, it is consumers and the general public that bear the brunt, should harms occur.'<sup>13</sup>

The swine flu fiasco shows the limitations of Cnidian medicine in real life. Risk assessment and management programmes cannot evaluate the imponderables: human life and dignity cannot be valued in dollars. Quantitive methods cannot even deal adequately with synergistic effects and are unable to assess unforeseen outcomes.<sup>14</sup>

To say that a risk is one in two, one in two thousand or one in two million is to make a statistical statement but to say that any risk is acceptable is a value statement and this can only be decided by community consensus, if the subject is one of policy, or by the individual, if it is a matter of personal health.

Doctors have no right to make value decisions on behalf of either the community or of patients.

A doctor may tell a woman that if she and her partner use a condom and spermicide the ideal risk of pregnancy is two pregnancies per one hundred years of woman-use but the real life risk is fifteen to twenty pregnancies per one hundred years. The risk if the woman uses a diaphragm and spermicide is ideally one to six pregnancies but realistically six to thirty. This is statistical information that a doctor may properly give.

But the decision as to what is an *acceptable* risk is entirely up to the woman or couple who are going to be taking the risk. Doctors must also remember that a one in a million risk that shows up is a one hundred per cent failure for the woman.<sup>15</sup> But the effects of a bad risk do not stop with the single event - they may go on for the whole of a person's lifetime.

Convulsive therapy by either drugs or electro-shock has been practised for mental disorders for some time and is still not entirely discredited.

Both forms of convulsive therapy are frequently complicated by fractures and dislocations resulting from the sudden massive muscular contractions of the tonic seizure. Fracture of the bodies of the fourth to eighth dorsal vertebra occur in about 20 per cent of the male patients and 5 per cent of the female patients. Such fractures may cause considerable pain and discomfort, but they are usually not disabling and do not, in the opinion of workers in the field, constitute a contraindication to further shock therapy.<sup>16</sup>

That's all very cool, calm and Cnidian. What of the patient?

Victor was raised in the Children of God sect and had difficulty finding hiss way in the real world when he grew up. His ECTs left him with several fractures and a bad back for life. This has been extremely costly for Victor and the taxpayer but, no doubt, correpondingly profitable for the medical-industrial complex.

Victor managed to get a teaching qualification and a job but, at the age of forty-five, he has had twelve operations to repair his back and just about ready to give up on surgery. He has lived in constant and worsening pain since his first iatragenic fracture and is now permanently on such a high dosage of morphine that pharmacists whistle when he hands in his scrip. He now feels grief for the drug-induced loss of capacity for normal feelings

#### INFORMED CONSENT

If doctors are to stop taking risks on behalf of the patient, they must learn to respect patient consent. Both doctors and patients have difficulty with probability decisions. One in two thousand sounds a good risk to Dr. Bruce Shepherd<sup>17</sup> but it is important to ask what the significance of the risk is to the potential victim. Surgeons have about as much risk of picking up AIDS from a normally antiseptic procedure as they have of being struck dead by a frozen fish falling out of the sky while they're playing golf - nevertheless, they loudly demand extra quarantees of their safety.

Little old ladies have every right to say they do not wish to take a one in-two-thousand risk with potent and only marginally useful new drugs.

At present doctors assume they are measuring an uncertain risk against a certain benefit but the efficacy of clean drugs is no more reliable than the safety of rogues: all drugs are produced by the same means. Remembering that most Me Too drugs offer little or no advantage over competitors, and most new drugs are only marginally better than old ones - if at all, we must assess not only the probability of harm but also the probability of benefit. Perhaps five per cent of drugs cannot be trusted because their clinical trials are invalidated by misconduct. Others are of such little efficacy that benefit can never outweigh risk.

The idea of informed consent was reinforced after World War II when it was highlighted in the principles of medical research on humans developed for the Nuremberg trials. Nevertheless, patients since then have often been deceived in the interests of experimental design that was intended to control for suggestibility. For example, patients in a double-blind trial of DES were told they were getting vitamins or not even told that they were in an experiment at all. 21

With university bioethics committees monitoring research proposals before funding is granted, the recognition of the subject's right to informed consent is increasingly guaranteed in academic research. However, there is no corresponding guarantee in clinical trials organised by drug houses.

There is a grey area where procedures are no longer entirely new but are still not fully proven. Many doctors are tearful that if patients exercised informed consent, all the excitement would go out of medicine - and some of the profit, no doubt.

Both doctors and patients might be better able to cope with best-case/worst-case choices that at least give the range and some indication of the realities behind the statistics. At the very least, setting up best and worst cases introduces a note of decent uncertainty to counter indecent optimism.

# **DOCTORS AND CHANGE**

Given that collaborations within the medical profession are slow and fraught with conflict, doctors are unlikely to reform their own practice with lightning speed. Australia-wide, doctors took twelve years and six editions to accept antibiotic prescribing guidelines produced in Victoria. The tenacity, patience, and passionate commitment of the doctors involved has been rewarded by the good reputation the guidelines now have. Professor Lloyd Sansom, Pharmacology, University of South Australia says "The guidelines ... are magic. [They have] made an enormous impact. In the interim, overprescribing and inappropriate prescribing cost the taxpayer rather a lot.

The first, hard-won model does seem to have made further initiatives less difficult. Psychotropic guidelines and editions for analgesic and cardiovascular drugs have also been produced.

It is difficult even to persuade doctors to agree on a title for a continuing education unit on prescribing: both 'Rational Prescribing' and 'Quality Drug Use' give offence because the former implies that current prescribing habits are not rational and the later implies that current quality is less than optimal.

Of course, both these implications are true but the explanation is not always to the detriment of doctors.

When the number of Serepax/oxazepam available on a Pharmaceutical Benefit Scheme prescription was reduced from 50 to 25 in an attempt to prevent addiction, the number of scrips doubled.<sup>24</sup> The Health Promotion Unit of the Victorian Health Department ran a campaign that offered relaxation, exercise, sleep hygiene and other forms of stress management.

This campaign, entitled 'Minor Tranquillisers Are Not Your Only Choice' and running in 1986-87, did achieve some reduction in the use of BZD but not an increase in alternative therapies. Prescriptions for antidepressants, painkillers, and anti-arthritic drugs rose, making an overall increase in drug usage and costs.<sup>25</sup>

The brutal fact, overlooked by some idealists in the bureaucracy, is that subsidised drugs are cheaper to the consumer than psychologists, physiotherapists, or sports centres whilst organising a hydrotherapy collective or finding a minimum-cost Tai Chi class demands personal resources that many people do not have. There is both a financial incentive and a convenience motive for drugs. Before government can reasonably expect GPs to prescribe non-drug alternatives, it must ensure that those alternatives are readily available at an affordable cost. <sup>26</sup>

Beyond the BZD issue, and the broader problem of rational prescribing looms the problem of fragmented effort. The House Inquiry submissions and interviews show that there is no shortage of information, energy or good will - only gross lack of co-ordination. With any luck the final report will provide an impetus for a national drug formulary and an effectively integrated service. But is a government report sufficient to generate change?

# THE DOCTORS' DILEMMA

The rebirth of feminism during the 1960s also involved the rebirth of the women's health movement. This could be officially dated from the 1970 publication of the Boston Women's Health Collective anthology, *Our Bodies Ourselves* which has been translated into many languages and sold many millions of copies. The movement is manifested in many lobby groups and self-help groups, new demands on health providers, the steady growth of women's health clinics and the increasingly pro-woman views in women doctors.

Alternative medicine is a growth area - even in forms that are not subsidised by health insurance. The practitioners of therapies like iridology, kinesiology, aromatherapy and the various schools of massage seem to be catering to a middle class who are sceptical about orthodox medicine, and willing to pay for less reliable therapies so long as they are also delivered with more compassion and less arrogance.

The unsustainable costs of Cnidian medicine, especially the pill bill, have forced government to consider economies while participatory democracy initiated by the Whitlam administration facilitates self-help and self-determination. Despite the bilious outburst by the then President of the AMA,<sup>27</sup> the Keating Government's 'Be Wise With Medicines' campaign is motivated as much by concern for people's well being as by a desire to cut costs.

The maladaptive expansion of (Cnidian) specialisations at the expense of (Coan) general practice seems to have been arrested and general practice has been refurbished as a specialisation in its own right - family medicine or community medicine. General practitioners now constitute a mixed group: ones who graduated before postgraduate training was available ones who have passed through it as a matter of choice and a group of would-be consultants who drop out and revert to general practice.

The innovating doctors who turned out for the Doherty Inquiry and the House Inquiry, and who publish little magazines to promote reformist views contrast with the resistance of traditionalists who, for example, obstruct initiatives of the women's health movement.

The Australian Medical Association fulminates against the 'Be Wise With Medicines' campaign but the Royal Australian College of General Practitioners is a participant.

#### **SOCIAL CHANGE AGENTS**

As I observed the awesome roll-call of agencies contributing to the House Inquiry, I was tantalised by the memory of a joke about the bay scouts and the old lady.

There was ACOTA, ACROD, ADEC and ADRAC followed by APAC, APMA, APSF and ASCEPT; DUSC seemed to have a fair bit of clout - more than ECC, HIC, or MLAM. (NDIS was discontinued in 1988 as a cost-cutting move.) OPAC, PBAC, PBS, and PEAC are still extant and PHARM recalls the heady days of Whitlam. POPPGOHS, RDNS, SACOTA, and SACPRPA, SHAPE, TDD, TPC, VDUAC and VMPF are all doing great good works.<sup>28</sup> These groups, and more besides, are helping to fix the prescribing mess.

And why did it take seventeen boy scouts to help the old lady across the road? Well - it seems - she did not want to go!

The larger the Organisation or institution, the more resistant it will be to change: the medical-industrial complex is enormous, enormously resistant and has been for almost one hundred years. Sometimes, resistance takes the form of frank opposition such as the industry's fight against the limited list of drugs in the British National Health Service and the fight, under Wyeth's leadership, to prevent WHO from persuading the UN Commission on narcotic drugs from scheduling benzodiazepines as drugs of addictions.<sup>29</sup>

Some of the programmes to monitor quality drug use rely on a database requiring information from community sources such as hospitals. The programmes are thus in competition with commercial databases that collect information to sell to the drug houses for use in marketing. The material is no longer available to government or to research agencies even on a commercial basis, and the commercial databases even suck up information that was previously available to research groups by paying for information that they used to get for nothing.<sup>30</sup> This may not be calculated resistance but it is as obstructionist as if someone had planned it that way.

The most crucial resistance the drug companies offer is their insistence on self-regulation. The next line of resistance is their influence over postgraduate medical education.

The doctors who exhausted themselves producing the antibiotic guidelines and getting them used are unsung pioneers. Now there are a great many more doctors working for change in different areas of medical practice: within repatriation hospitals, nursing homes, alcohol and drug abuse programmes, in family medicine, and in medical education.

Even so, there are not enough of them to turn the whole profession around. The AMA, denying even that there is cause for concern, had not yet engaged in the debate proper. Some doctors even oppose debate in principle.

The Couchman Show had a simple format: Peter Couchman moderated discussion of some contentious issue among an audience selected to represent a spectrum of views on the subject. The show aims for even-handedness. Even so, a psychiatrist tried to stop him discussing benzodiazepines because she believed that lay persons should not discuss medical issues.

Similar objections to public participation in health issues were once raised against the extension of the vote to blacks and women. The argument is, of course, circular: we can't inform people because they are ignorant but unless they are informed they will remain ignorant.<sup>31</sup> Not all doctors think this way.

'We believe,' writes Charles Medawar, 'that the public is capable of understanding well enough what standards of safety apply - and that the major obstacle to better understanding is lack of cooperation and obstruction by the providers themselves. The providers generally do not welcome scrutiny and protect themselves from it by custom, practice and law.'<sup>32</sup>

At the very least, the public should be included in planning schemes for quality drug use. The House Inquiry heard that there is widespread recognition that poor compliance is as much a problem as unwanted effects.<sup>33</sup> Change is needed in consumer education<sup>34</sup> and the idea of a therapeutic team is being extended to include the providers and the patient.<sup>35</sup>

But there is no quick fix for patient ignorance any more than for doctors: educational leaflets are rapidly lost;<sup>36</sup> there are about forty different medication management cards - and they do not work;<sup>37</sup> packet inserts are hard to read, hard to understand and hard to file.<sup>38</sup>

Moreover, the consumer's role goes beyond learning compliance. Consumer review of health care delivery could make up for some deficiencies in peer review. American consumer groups - most notably DES Action - have shown that the public can exert influence effectively.<sup>39</sup> The turnaround on promiscuous benzodiazepine prescription occurred largely because of judiciously expressed community outrage.<sup>40</sup>

The aged are a well-organised, vocal and innovative subset of consumers. Their main message is that ageing is not synonymous with illness and that fifty per cent of hospitalisation among older people is due to over medication, inappropriate medication and medication mismanagement. The aged are producing their own educational programmes and drug use guidelines.

For example, the Older Persons Action Centre devised the Australian Drug Guide 'to get ourselves out of the morass about what standard of information there should be and who decides it ... it is all open to negotiation ... to use this book as a starting point and then negotiate from a definite place which at least suits consumers.'43

The Australian women's health movement has been enormously successful in establishing around fifty clinics that offer a paradigm for primary care. 44 Steady pressure group action has succeeded in modifying attitudes to menopause, childbirth and other conditions peculiar to women and publicising demands that doctors investigate and record child abuse, domestic violence and sexual assaults more effectively. The Endometriosis Association's presentation to the House Inquiry is a painful cameo of women's complaints about how medicine deals with female problems.

Two local studies reported long intervals of desultory investigation, averaging 6.9 years between presentation of symptoms and diagnosis, with some women getting the run-around for as long as twelve years. The most aggressively promoted drug, Winthrop's danazol, is prescribed most frequently while information about other drugs such as Provera and Duphaston is crowded out. Information is withheld about danazol's unwanted effects, including weight gain, muscular cramps, acne, facial hair and irreversible virilisation of the voice.

Information on side effects that was publicised in America in 1982 did not become available in Australia until 1990.

Women are dissatisfied with the general 'there-there girlie' attitude of the medical profession about what is an extremely painful and disabling condition.

'What the medicos think that women need to know is generally not at the same level that women want to know,' Rosalind Wood of EAV told the House Inquiry.<sup>45</sup> This is why EAV has issued its own leaflet on endometriosis.

The women's health movement is also concerned about biases in the general conception of women's health and in research. Funding usually goes to research in reproduction yet women themselves are acutely aware of industrial health and safety issues, most of which are not researched. Women also locate their health problems - and those of their families within a socioeconomic environment, emphasising the importance of clean air and pure food and water, as, indeed, they have done for over a century. Little boys are Cnidians and little girls are Coans.

Will things be any different now that women doctors graduating from Australian medical schools have just about reached parity with men? Possibly the influx of doctoresses into the community will introduce a Coan tendency. The quality and style of care among Coan doctors meets the ideals set up by the women's health movements in both the nineteenth and twentieth centuries.

These reformers tended to see health in holistic terms and to promote Coan solutions as more effective, more humane and more cost-beneficial but reviewing the successes and the failures of the women's health movement in the last hundred and forty years, one could argue that we seem condemned to triumphs of masculine, Cnidian, curative medicine over feminine, Coan, preventive medicine.<sup>46</sup>

The belief that women will somehow do things differently from men arises from a belief in basic differences between the sexes, ascribing nurturance, compassion, conservationism and foresight to the female and tough-mindedness, rationality, destructiveness, and tunnel vision to the male. Obviously, these stereotypes will not hold up to academic or political scrutiny.<sup>47</sup>

Nevertheless, the sexes do differ in a number of measurable ways and two of these - communication and management style - are crucial to the practice of medicine. They will become more influential as more medical schools include communication skills and practice management in the curriculum.

Ask Blind Freddy. Ask Joey the Goose, the drover's dog, and the bloke on the Bourke Street tram. It doesn't take a giant intellect to see that if a faculty selects students for their ability in maths and physics, students will more than likely be good at maths and physics. What do maths and physics have to do with healing? These recruits may or may not - more likely not - be the wise, warm, articulate, astute, supportive, sensitive, sensible, patient practitioners that sick humans need.

My friend Piers was a Coan doctor in a Cnidian school.

'When all the first-years were lined up, the Dean explained that we had the highest entry scores of any intake at the university. He looked us straight in the eye and told us we were extra special. I thought, "What an incredibly astute fellow."

'Eventually, I got on the wards and saw what they do to the patients. Then I knew I could never be a regular doctor. I work part-

time and play in a chamber-music group the rest of the week. I rely on intuition a lot ... any patient who wants their records may have a copy (I need one myself for legal purposes)...

'I'm rather good with addicts ... I don't take anyone on unless we like each other and we work out a contract - then we both know what we have to do and whether we've done it. I'm friends with all my patients. Sometimes I don't prescribe anything - just being there does the trick. I think I'm a healer now.'

Doubtless maths and physics have value for research scientists but doctors need to be able to deal with sick and unhappy people. Obviously some indicators of an aptitude for healing must be included in interviewing for entry to medical schools.

The simple modification of prerequisites for entry to the medical course can induce far-reaching change. Dropping pure maths has permitted large numbers of women to train as doctors. Making interpersonal communication skills a prerequisite would also be beneficial <sup>48</sup> - it would favour a different kind of male from the ones who take twelve years to diagnose endometriosis and think that beard growth, anabolic weight gain and a five-tone lowering of the voice are acceptable unwanted effects.

Pharmacists are effective change agents, particularly favouring a team approach to prescribing. In both commercial and hospital pharmacies, they are developing ways of improving service while cutting costs. As nursing becomes a profession and nurses are less willing to play Florence Nightingale to overweening doctors, nurses also want to be part of a team. Both the Australian Nursing Federation and the Royal District Nursing Service suggest that effective nursing requires greater autonomy in drug managements.

Eventually social change must involve government. The very occurrence of the lengthy House Inquiry into the Prescription and Supply of Drugs bespeaks a commitment within government to seek better services at the cost of fewer tax dollars. But government faces the same problem vis-a-vis the medical profession as do nurses: doctor-deafness. Dr. M. L Mashford, Chairman, Therapeutics Committee, Victorian Medical Postgraduate Foundation, believes that federal initiatives have 'to be promulgated to people by their colleagues.' Dr. Ken Harvey, La Trobe University, confirms that local representation is vital 'because things imposed by Canberra without local representation are often rejected on principle.'51

Since the medical profession confuses bureaucracy with government, substantial agreement on the need for a national approach to the quality of drug use coexists with massive mistrust of government. According to Mary Hemming, Executive Pharmacist, Victorian Drug Usage Advisory Committee, a national drug policy must have government activities, industry activities, health provider activities and consumer activities. The separate initiatives from the states and the Royal College of General Practitioners was identified as one area needing co-ordination and nurture. Activities

Government might woo the co-operation of that minority of doctors who belong to the AMA by responding to concerns about shrinking incomes and oversupply of doctors. Since the perception of overworked doctors falling into poverty is being used as propaganda for AMA Policy, an hours and incomes survey should be conducted by government and interested bodies.

But we cannot say how many doctors are too many without first asking how many there are.

Although the AMA, claims that there are too many overseas-trained doctors and various anecdotes suggest that GPs are not earning enough, no one knows how many doctors there are or what they are earning. Guesses - ranging from thirty-six to forty-three thousand - are hardly precise enough to support policy.

Many contributors to the House Inquiry were buoyant with anticipation of change and reports of change in the offing.

'A change in attitudes is really beginning to develop,' said Dr. Tony Adam's, Department of Health, Housing and Community Services, Canberra. 'There certainly is a wave of enthusiasm and cooperation amongst all players at this point in time.'55

Denise Swift, from the Pharmaceutical Benefit Branch of Health, Housing and Community Service, summarised the state of play. 'What the committees have done is put it on the agenda, not only on the agenda of government, but on the agenda of most of the key players, including the health professionals and the consumers. That is not a hard change in terms of drug utilisation at the moment, but I think it will filter through, because awareness is the first level we have to get to.'<sup>56</sup>

### **FACT FACTORIES**

In this life, we want nothing but Facts, sir; nothing but Facts!

Thomas Gradgrind

Education is the recognised panacea for social ills. In the case of doctors, who have already enjoyed a generous helping of expensive, but inadequate, education, the panacea must include continuing education. *The Doherty Report* found significant weaknesses in continuing medical education services in Australia:

- utilisation is low
- programmes are poorly designed
- services are under-resourced: 'some of the fund sources, in particular pharmaceutical companies, are unpredictable and their distribution of funds is uneven.'<sup>57</sup>
- 'we have no effective mechanism whatsoever for putting remedial education out to every last medical practitioner from the back of Bourke to the outer suburbs of Melbourne, Sydney or Brisbane. 58

Now, the necessity for remedial education derives partly from deficiencies in existing medical curriculums and partly from disinformation circulated by the pharmaceutical industry. It would seem logical to forbid industrial intervention in medical education by law but to permit strings-free donations to government educational initiatives. If the drug houses then say they'll take the football and go home, independent medical education can be paid for from the savings in the pill bill.

The *Report*, set up to examine formal education, had nothing to say about the role of detailers in postgraduate medical education - yet they are overwhelmingly the dominant source of information about drugs for most doctors. The availability of detailers as a source of both prescribing information and encouragement helps explain both the unevenness of continuing medical education and an apparent indifference to it among doctors. Perhaps, also, the education of doctors fails to give them an urgent sense of how quickly knowledge becomes obsolete. By contrast, pharmacists are enthusiastic about postgraduate education, presumably because they are aware that the drug market is changing all the time. <sup>59</sup>

Tasmania has requested Commonwealth funding for a scheme to create a system of preceptors among general practitioners who will

participate in teaching programmes for both undergraduates and graduates.<sup>60</sup> Like vocational registration and many projects cited in the House Inquiry, the Tasmanian scheme is ingenious and inspiring but as yet untried.

Doctors, in common with stevedores, are slow to see that continuing education is an opportunity - not a threat. The College of General Practitioners is aware of this obstacle and tries to neutralise it. 'We take as a starting point that general practitioners are professionals who are doing a good job and trying to do a good job and what we are doing is trying to aid them to do a better job because everyone has room for improvement.'

The problem is not only the obsolescence of knowledge. *Doherty* found that undergraduate courses are severely limited - medical schools are deservedly called 'fact factories'. High-tech hospitals are not the best setting for training GPs. When they get out into practice, they have to unlearn inappropriate behaviour that they have acquired in during hospital training.<sup>62</sup> They are also exposed to detailers.

The pedagogy of most medical schools is archaic so that the rigid undergraduate education endured by most doctors now practising actually handicaps them for continuing education. Many doctors find journals such as the *Medical Journal of Australia and Australian Prescriber* heavy and difficult.<sup>63</sup>

This has been attributed to their tiredness after a hard day's work but it is more likely because rote learning as undergraduates has crippled them for self-directed learning as practitioners.

A major thrust of the undergraduate curriculum should be to provide the young undergraduate with the ability to critically appraise his performance and the performance of his peers and to use these skills to continually improve his standards ... As well as learning the basic skills of communication, and the principles of both preventative and curative medicine, the medical graduate must understand the rigors of scientific method . . .'To achieve this in the undergraduate curriculum ... less stress should be placed on rote learning and more on interactive teaching programmes, problem solving exercises, teaching of communication skills, and interaction with other health professionals.<sup>64</sup>

Criticisms of rote learning and emphasis on problem-based training came up repeatedly:

Problem-based learning requires the development of an educational programme around a set of problems, giving emphasis to the identification and the solution of the

problem, and to the insights into the process of efficient and effective diagnostic thinking ... Problem-solving is the day-to-day activity of medical practitioners.<sup>65</sup>

There should be a de-emphasis of didactic teaching, and increasing emphasis on preparing students for a lifetime of further education. This can only be achieved by encouraging active, independent, self-directed learning ... there should be a reduction in lectures, a reduction in scheduled time, and an increase in problem-solving activities appropriately evaluated. Most medical courses supply the answers before the students have asked the questions. <sup>66</sup>

The long-term effects of being surfeited like a sumo wrestler in undergraduate education is that when doctors come to continuing education, they expect to be spoon-fed information, rejecting more reflective critical approaches.<sup>67</sup>

General practice varies considerably across Australia so each GP should undertake self-assessment in options for continuing medical education. Yet, according to Dr. Barbara Booth,

... GPs find that a difficult process to go through. They have never learnt self-assessment in undergraduate training and only those who have gone through the family medicine program have learnt it in their postgraduate or hospital training. They feel they need more guidance ... in what they should be doing ... It is undergraduate; it is childish . . . So we have this difficulty, when all continuing education is voluntary, that what appeals to people and what people go to tends to be a lecture format that they are used to and adding new information, whereas the more interactive formats than encourage them to look at their own practice and improve it are perhaps not as popular. 68

Continuing education partly depends on how doctors perceive their needs but there are no criteria of excellence or system of peer review to make sure that doctors practice the standards they were taught or to diffuse innovation. The Health Insurance Commission is currently working with professional bodies to develop standards for peer review and a number of professional bodies are working on the problem of keeping doctors up to date.

The House Inquiry found strong consensus that the ownership of any quality control system needs to rest with the practitioners. 'There is a lot of evidence that people who have been involved in standard setting exercises find the whole process therefore a lot more acceptable. The difficulty with that is that again you have got the balance between a credible standard that is very strongly grounded in research evidence and just a consensus which makes common practice the standard, and common practice may be totally wrong.<sup>71</sup>

Pending long-term solutions, such as appropriate undergraduate education, universal continuing education, the national drug formulary and an effective system of peer review, a number of short-term remedies are available to doctors now.

# **BAND-AID SOLUTIONS**

One of the simplest and most effective lessons a doctor can learn is how to get the most out of computers. They can work at a speed that makes them an attractive time- and labour-saving device for the busy practitioner but computer technology can do a lot more than merely keeping track of patient accounts. Although they will not solve every problem, they can assist in preventing harm by tracking overprescribing and the prescription of incompatible drugs.

# They can also:

- organise complex monitoring
- co-ordinate records of patients attending more than one doctor or pharmacist
- aid diagnosis by a systems approach that could easily and economically be incorporated into medical practice by the use of appropriate algorithms.

Since twenty per cent of adverse drug reactions are due to interactions between drugs, and sixty per cent are due to inappropriate prescribing,<sup>72</sup> the use of computers could be a valuable stop-gap reform while doctors learn how to prescribe.

The Pharmaceutical Health and Rational Use of Drugs Working Party (PHARM) is looking at linking doctors and pharmacists by a computer database holding patient records. They envisage a voluntary system like the Pap smear registry, which gets about an eighty to ninety per cent agreement rate. Martindale's internationally renowned Pharmacopoeia is one of only two sources ranked as 100 per cent reliable by local GPs (the other source is hospital pharmacists). Martindale is available on disc and could easily be used - as it was during the Gulf War - to guide prescribing decisions. The property of the partial pharmacists of the prescribing decisions.

The pathology ordering profile is a provocative scheme. Like a calorie counter, it educates without coercion simply by collecting figures on what procedures are requested by doctors and making these statistics available to those whose rates are unusually high.

Practitioners can see where their own practice stands in relation to the mode and, with a very little discussion of alternative procedures, modify their own practice. In 1990-91 pathology growth was 10.6 per cent; for 1991-92 it was 1.1 per cent. This method of data collection and feedback could work equally well for pharmaceutical prescriptions.<sup>75</sup>

For the last ten years or so, some medical students have been trained to assess the information given by commercial detailers. Adelaide leads the way: 'The clinical pharmacists, I think, really contribute very significantly to that gaining of wisdom in those few years that we have the doctors with us in their training phases.'<sup>76</sup>

Currently, the capacity to appraise a detailer's presentation is very variable. In Sydney, students are trained to cope with commercial detailers by role-playing and by meeting commercial detailers only in the company of senior members of staff. Students also learn how to critically analyse promotional literatures.<sup>77</sup>

Detailing is perhaps the only area in which medicos might be shamed into better practice. There they are, with one of the most prestigious and expensive of educations to justify their claim to elite privileges but they rely on detailers who may have no better qualifications than basic literacy and a driving license or possibly basic literacy, a driving license and a twelve-month course in sincere lying.

Could doctors be shamed out of standing in relation to drugs as consumers stand in relation to soap powders and shampoos?

The more doctors rely on commercial sources of information, the more they are liable to irrational prescribing. Despite cosmetic claims that the purpose of detailers is to educate as well as to sell, one finds revealing management comments to the contrary. Dr. Dale Console, former medical director of Squibb (the firm that collaborated with Ely Lilly to launch DES)<sup>78</sup> said 'The primary purpose of the detailman is to make a sale, even if it involves irrational prescribing . . .'<sup>79</sup>

So far, no-one has devised a better way of modifying a graduate doctor's conduct than advertising and detailing but using the methods of the detailers to undo their own work can succeed - at least temporarily. Teaching pharmacists in both Adelaide and Sydney are finding that written material alone has little impact on prescribing practices but a brief educational visit supported by appropriate written material (academic detailing) is allegedly effective in both the short and long term. 80

Regrettably, several academic detailing pilots show good initial success followed by reversion to previous bad habits because academic detailing cannot compete with commercial detailing.<sup>81</sup> Academic detailing is also a very expensive way to change practice<sup>82</sup> at least partly because whatever an academic detailer does must be reinforced constantly.<sup>83</sup>

Audit activities are also effective temporarily but doctors do not internalise their new leaming. Training doctors to prescribe drugs that give the same benefit at lower cost also works at first and then reverts. Five years after they go out in practice, Dr. Jekylls who prescribe generics while they are interns become Mr. Hydes prescribing brand names - and they choose the most heavily promoted brand names which are also the most expensive.

There may be no truth to the allegation that doctors generally believe that they are above economy and that government ought to sustain health costs ad infinitum.<sup>86</sup> At any rate, attempts to educate doctors in prescribing generics can be undermined by promotional drives aimed at establishing brand loyalty.<sup>87</sup>

The sad fact is that industry has more money to corrupt doctors than the public purse can raise to educate them. Dr. Ken Harvey told the House Inquiry that the promotional power of industry is about 15 per cent of sales or \$200 million annually including \$40 million for detailers or \$8,000-\$10.000 per prescriber. At present, the total medical educational effort comprises \$2.6 million from a total budget of \$1 billion in the Pharmaceutical Benefits Scheme plus other funding in bits and pieces. Beautiful billion in the Pharmaceutical Benefits Scheme plus other funding in bits and pieces.

Drug houses have been suborning doctors since at least 1900.<sup>90</sup> It is time the medical profession broke free.

Several doctors who testified to the House Inquiry reported that they do not see detailers. Since almost no new drugs are totally original and few have significant edges over their competitors, and since detailers are trained not to enter into discussion with anyone who appears to have scientific knowledge about contentious issues, <sup>91</sup> there is really nothing to be gained from seeing detailers except gewgaws and flattery. No patient was ever cured by a unique selling proposition.

Selected hospital pharmacies could provide a more reliable service if they were funded to expand their in-house drug newsletters for circulation to the medical profession. Doctors would do better to invest the time they formerly gave to detailers to stress management or continuing education.

In other words, doctors should boycott detailers.

If only five per cent of doctors undertook a well-publicised boycott, it would frighten the bejazes out of the drug houses and significantly improve prescribing.

Possibly vocational registration will be an incentive for doctors to undertake further courses<sup>92</sup> but, if my hypothesis that undergraduate rote learning disables doctors for continuing education is correct, it may be that postgraduate education will always have a high failure rate because it must be considered as remedial rather than just updating. Remedial education is never likely to be as effective as good grounding first time round so, for significant change, we must look to a long-term solution: the reform of undergraduate medical education.

The Doherty Report was terse about the implications of its finding that general practitioners were not appropriately educated.

Either...medical schools abandon their attempts to produce general practitioners...[or] re-examine whether the selection and training of students in the medical school best suits the needs and demands of the primary care practitioner ... the medical schools will have to attempt to match more carefully the quality and type of their output with the health care needs of society.<sup>93</sup>

The recommendations were calculated not to standardise but to rectify, expecting that the medical schools will address themselves to the issues with a variety of innovations carrying hopeful implications for long-term social change.

#### MEDICAL SCHOOLS AS A FORCE FOR CHANGE

The solution to iatragenic illness is not only making safer drugs but making drugs safer: Dr. John Griffin, formerly of the British Department of Health and now of the Association of the British Pharmaceutical Industry, says that twenty per cent of adverse drug reactions are probably due to the drugs themselves, twenty per cent due to interactions between drugs, and sixty per cent are due to inappropriate prescribing.<sup>94</sup>

In other words, industry is totally responsible for the rogue drugs and that part of the medical error that derives from disinformation, while the medicos are responsible for negligent prescribing and relying on the industry. The overwhelmingly greater responsibility lies with doctors.

Medical teaching has not evolved to cope with the geometric expansion of scientific information now considered necessary in medical courses. Instead of teaching methods of accessing the ever-growing body of relevant knowledge, most schools have simply increased the burden of rote learning.

Many medical students, suffering from information overload, become cynical as they are subjected to Dickensian teaching methods that are probably discordant with their previous experience as the brightest and the best of university intakes and may actually be destructive of their initiative and creative talent.

Rote learning of copious details is not conducive to the sort of detective work required for astute diagnosis because material learned parrot-fashion during the preclinical years is not easily retrieved in clinical training when theory should inform practice. That is, students have laboured to install a database that they find they can't access. According to educationalist John Biggs, 'teaching often focuses on what is testable, rather than on what is complex, interesting, or functionally important. Since most medical courses are not taught by practitioners or by teachers but by people with research expertise the learning outcomes are not good for the students or their eventual patients. The classical scientific approach of controlling for all but one variable at a time is not appropriate for understanding either complex sociobiological systems involved in sickness and health or their socioeconomic context.

The defects in medical education are particularly relevant to prescribing because that comprises the bulk of medical therapy in general practice. Many Australian medical schools do not even have a chair in clinical pharmacology and many are allocating only about one quarter of the hours needed for an elementary understanding of drugs. Moreover, the number of drugs available is increasing each year but the number of hours devoted to teaching pharmacology remains static. The average general practitioner has had about one hundred and twenty hours on drugs whereas most pharmacists have had two thousand hours.

Yet pharmacists are expected to defer to doctors on prescribing!

This deficit in undergraduate education obliges graduate doctors to depend on detailers to do their homework for them. Some medical schools are alert to the problem and PHARM is promoting an undergraduate programme, which will be offered to all the medical schools, to improve the quality of prescribing skills within the context of the consultations.<sup>98</sup>

Both the University of Adelaide and the University of Sydney have established programmes to raise the standard of drug education for undergraduate doctors. <sup>99</sup> These schemes encourage co-operation between the doctor and the pharmacist to educate the patient in effective and safe drug use.

Dr. Ross Holland, Dean of the Australian College of Pharmacy Practice, believes that innovations in Sydney are beginning to show results. 'The barriers are breaking down and in a large part this is due to the fact that the newer doctors particularly are going through a hospital system where the hospital pharmacists are with them on the wards and they get used to talking to pharmacists and seeking advice and acting as a team. That is beginning to show in the community now.'100

Dr. Barbara Booth sees intellectual improvement. 'In running critical appraisal sessions or just questioning lecturers ... those coming out of FMP training are far more critical and by far more acute in questioning and formulating their own ideas and asking for the research to base decisions on than some GPs who have been in practice for a while. Mind you, the GPs who have been in practice for a while have perhaps a lot more common sense."

There is also a serious defect in the way medical teaching is structures The conventional division of disciplines within a faculty and the distribution of subjects over the years of the course leaves many cusps where problems requiring a multidisciplinary approach are lost. The student gets only one perspective on an issue or a fractured perspective. Many important features of the BZD scandal were due to relevant areas being abandoned in the cusps of course structure. The major specialisations involved with BZD include pharmacology, neurology, psychiatry, surgery, women's health, and community medicine.

The Monash University medical faculty eliminated oversight and overlap by restructuring its six-year course over a three-year period. The Curriculum Review Committee has the ownership of an immense

database containing the whole undergraduate curriculum to ensure integration of courses vertically (by discipline) and horizontally (by year), thus avoiding both overlaps and gaps.

New organisation and new content requires new teaching methods. Monash has also reduced contact hours during the first three years, in line with Doherty recommendations, to achieve not less learning but a different kind. The course discourages traditional rote learning, replacing it with self directed learning. The structure breaks down the traditional division of preclinical and clinical or abstract and concrete phases which left students unable to integrate knowledge and practice. Science and clinical competence are now taught in wedges from day one with more emphasis on systems in years one through three and on departments in years four through six.

The new curriculum is delivered at a more everyday level than hospital high tech. Community medicine is increasingly prominent in the course and, from first year, students have clinical contact visits to pharmacists and GPs - including a rural general practice.

Monash no longer bases selection on VCE alone but looks for motivation, cognitive style, and suitability for the study and practise of medicine. The three-person interviewing panels include lay people. The University is also looking at entry of students from other courses. Newcastle has already established adult entrance and a Koorie quota while Queensland, Sydney and Flinders are considering the American model - an intake of degree holders.

Doctors do not talk to patients - or anyone except, perhaps, other doctors. Doctors do not listen to patients or anyone except, perhaps, other doctors, accountants, and lawyers. Doctors not only do not talk and do not listen, but they set up the ground rules of communication in such a way as to prevent the other person speaking.

Having said that, I remind myself that I should amend the generalisation to read 'male doctors' but the reality is that, at present, there are simply more male doctors than female. The typical doctor - not the stereotypical doctor - is still a reluctant and inept communicator.

If you think I'm exaggerating, go back to Oliver Sacks. 103

Nurses and paramedics and pharmacists and patients and office staff and politicians and hospital cleaners and other doctors' wives put this down to arrogance. I wonder if the explanation is not more complex?

Could it be insecurity? Rote learning is the least reliable learning known to pedagogy - it is prone to be forgotten and it is hard to access in any meaningful way. I have noticed repeatedly that when doctors communicate in strings of facts, they are likely to be as fluent, confident and relaxed as a magician producing a stream of coloured handkerchiefs out of his ear. When they can be coaxed into a sender/receiver conversation many of them are as awkward and anxious as a wombat crossing Niagara Falls on a monocycle.

The twin arts of talking and listening are taught in every year of the undergraduate Monash course and in five of the six years of Social and Preventive Medicine. The syllabus includes communicating with non English-speakers, the disabled, and the intellectually disabled.

Communication skills means acquiring the skills to communicate, it is different to learning about communication skills. In a sense it is like first aid. To be successful in first aid, you have to be able to do it. To just know about it, but not actually to do anything, is a useless exercise, so we have training; we use role-play techniques. We use role-play between students; role-play between students and their teachers. We use dummy patients, standardised patients who are actors or local patients who wish to be involved, and we use real patients. We use video feedback and we have a formal assessment. So it really is a very sophisticated program. 104

Not all sick people can wait to see a doctor who graduated from Monash since the new curriculum. Until older graduates catch up with continuing education, consumers would do well to go to women doctors or community medicine clinics or look for a self-help group in any disease they may have. For those random complaints, consumers should simply practise communication skills and assertiveness to set the ground rules for themselves.

#### **BAD APPLES**

Any honest housewife could sort them out, having a nose for fish, an eye for apples. Is it any mystery who are the sound, And who the rotten?

**Robert Graves** 

TMe history of medicine is not much taught in medical schools possibly because 'so much of it is an embarrassment'. <sup>105</sup> Let us scamper through the history of iatragenic addiction.

- Alcohol was the first addictive substance prescribed by modem doctors - openly as a tonic or as an unseen component in medicines.
- The British National Health Scheme continued reimbursing medicinal alcohol until 1984. Until very recently, addiction to alcohol was seen as a weakness of character or of personality.
- Opium has long been used as a strong painkiller and in the nineteenth century it was used to treat alcoholism. Since the drugs were unrelated, the cure did not work - however, the patient might end up with two addictions instead of one. Happily, these could be maintained with laudanum - a solution of opium in alcohol, much favoured by Sir Walter Scott.
- From about 1850, doctors enthusiastically used morphine to treat both alcoholism and opium addiction, believing the safe, new drug to be non-addictive. Their labours were made easier by the invention of the hypodermic syringe in 1854, which was adopted widely by the military. During the American Civil War, morphinomania was called 'soldier's sickness' and many veterans were discharged with syringes and a supply of the drug. Syringes for ladies began to be designed in the style of fashionable jewellery.
- Coca was introduced to the United States in tonic preparations for the shy young. By about 1880, doctors were using the glamorous, new, safe American drug, cocaine, to treat morphinomania. Once again, cure was inherently impossible because of differences between the drugs but once again, the risk of dual addiction was likely. For once, the newer drug's addictive properties were recognised and publicised early.
- Chloral hydrate was introduced as a very safe sedative-hypnotic in its own right in 1869 and was already out of favour by 1900 although it is still available. In its time, chloral was used to treat alcohol, opiate and cocaine addiction but it was notoriously easy to overdose.
- By the turn of the twentieth century, diamorphine better known as Heroin, the hero drug developed by Bayer in 1898 was being used to conquer all the other addictions. Heroin itself was said to be wonderfully safe especially for babies.
- The bromides were used for epilepsy and as an anaphrodisiac and sedative from about the time of the Crimean War until well after World War II. They were promoted as safer than choral and nonaddictive. By 1950, despite early warnings, about ten per cent of all admissions to British psychiatric institutions in the 1950s were related to bromism. Evelyn Waugh's unpleasant personality could be explained by his bromism.

- In 1903, Bayer's Veronal was the first of many barbiturates to be marketed. Within a few years, its claims to perfect safety were challenged by reports of deaths and by 1913 it was one of the ten drugs most frequently implicated in fatal accidents and suicide. The controversy over deaths and addiction raged until, the arrival of the BZDs.
- The benzodiazepines were, of course, bruited as much safer than the barbiturates and a safe alternative to alcohol. It will be interesting to see how long some of them can remain now that the World Health Organization has succeeded in having them grouped with their predecessors as drugs of addiction. With the increasingly fast circulation of information, the interest of government in health, and the growth in consumer advocacy, BZDs are unlikely to last as long as the bromides but they will probably survive into the twenty-first century. The novel and encouraging feature of BZD history is the strength and extent of consumer protest.

This brief history reveals a common pattern: at first a new drug is puffed as wonderfully safe and effective; after a surfeit of optimism, it is said to be addictive, potentially lethal, and possibly ineffective as well; controversy rages; startling ignorance of chemistry and want of common sense is revealed among doctors; controversy is not settled by accepted scientific procedures but by the arrival of a replacement drug; the new drug is welcomed because it both supplies a need for a sedative-hypnotic and either cures the problems caused by the current drug or is believed to be safer and more effective; it is puffed as miraculous ...

The new cycle is starting up with the broadened indications for tricyclic antidepressants, and the arrival of new drugs. We watch with eager anticipation to see whether Buspar/buspirone and Zimovane/zopiclone, now being promoted as safer replacements for the BZDs, will follow this standard pattem. At least the blatant advertising at the expense of women has slowed down but marketers are still selling the image and not the product. Buspar used a swan and Zimovane used a teddy bear but the message is still You can trust this drug.

Government, doctors and consumers alike should treat this claim with extreme caution like other classic lies, 'My cheque is in the mail', 'No new taxes', 'I'll only put the head in' and 'I won't come in your mouth'.

The trouble with marketers is that they believe they can market hoop snake oil - and they often succeed. Hence, they will go ahead with doubtful products, and rely on promotions to change the product's image rather than changing the product or giving it up as an interesting idea that failed.

When word got around about danazol and women began to refuse to use it, Winthrop ran a survey to explore their attitudes to the drug and its unwanted effects. The company could not understand what women do not like about facial hair, deep voices, muscular cramps, anabolic weight gain and a very doubtful benefit. Its response to their response was to run a seminar for gynaecologists at the Hilton where an American expert demonstrated that a really vigorous exercise program reduces side effects. He based his argument on the results from five women. The company did not need to run a seminar for women because, in marketing terms, the doctor is the consumer who must be persuaded.

One curious feature of the recurring pattern of addictive drugs is societies need to condemn some drugs as addictive, toxic and to be avoided while retaining others for promiscuous use.

Although Dr. Minty had so little to offer, I sometimes used him as a subsidised sounding board for my own thoughts about my (increasing) problems. When I encouraged my son to go into residence at university because I no longer had the energy to mediate between him and his stepfather, I was shocked to find two disturbing documents in the, shambles of his old room.

One was a well-turned poem about the experience of hallucinogens (which turned out to have been written by someone else) and the other was a scratch list of experimental drugs, both legal and illegal, ranging from Rohypnol through psylocybin to heroin but excluding cocaine. I was disturbed but not panic-stricken to find that he was a member of the Greater Public Schools Junior Junkie Circle - a group of boys whose parents were professionals, permitting them easy access to publications such as MIMs and to both the pharmaceutical drug culture and the cannabis counterculture.

As an appendix to a discussion about divorce, I asked Dr. Minty to identify some of the unknown drugs on the list, which he did. But his reaction was unusually energetic, decisive and directive.

'Forget about your husband!' he said. 'Think about your son!'

Already far gone in Ativan addiction without knowing it, I had dragged myself to the doctor on my own behalf. I was essentially dependent on my husband since his professional income subsidised my writer's pittance. At the time, I resented the doctor's blatantly sexist refusal to consider me. Now, I scorn his hypocrisy in condemning recreational drugs while pushing his own.

Obviously the corporations profit more by a drug that creates an appetite for itself, but why should doctors need to prescribe known or suspected drugs of addiction? Among the many idiosyncratic reasons they have for giving a prescription, several stand out as relevant to mood altering drugs.

Prescriptions are more likely to be given if the quality of the doctorpatient interaction is unsatisfactory. Doctors offer prescriptions in response to being inappropriately asked to act as social workers as well as to close an interview and affirm professional competence. Some prescriptions seem to be an outcome of the doctor's own states: the longer the doctor's day and the less job satisfaction s/he enjoys, the more prescriptions are written. Writing a prescription is a quick alternative to practising medicine.

Prescriptions reflect the doctor's attitudes, values, and philosophy more than the patient's condition. Doctors who cannot communicate, have no alternative to offer, want to please, and cannot tolerate anxiety themselves prescribe more BZDs. Repeat prescriptions are known to be the habitual outcome of a particular doctor-patient relationship, a stereotyped response that may be especially relevant where the patient is elderly.

Many BZD prescriptions are written to put the doctor out of the patient's misery and more to put the Cnidian doctor out of his misery at having to deal with problems that cannot be solved in isolation from the whole person and his or her social context - that is, the problems best treated by Coan medicine.

The benefits to the doctor of an all-purpose drug for wastepaper basket disorder far outweigh any putative harms to the patient. As the advertisement said, 'Whatever the diagnosis - Librium.' This advertisement, which appeared in the *British Medical Journal* during 1969, showed only a close-up of a male hand feeling a female pulse.<sup>109</sup>

NOW is the time to stop the addictive drug cycle.

The time to stop the addictive drug cycle is NOW.

Government must recognise that self-regulation is a license to put profit before people. The industry is too big to beat but while government pays the drug bill it has a splendid weapon to force compromise solutions.

It is premature to suggest how this is to be done in Australia when the government is still responding to the House Inquiry but the general principle is that government should insist on a bigger say and fund regulating authorities for an expanded and more aggressive role. In the meantime, the minimum first step is to follow the WHO lead and schedule BZDs as addictive.

Some very simple solutions to the addiction problem can be executed immediately. Where addictive drugs are concerned, industry has historically provoked concision over terminology to bamboozle government. The debate over personal dispositions, habituation, dependency, addiction and so forth must stop. Cross-dependency can be used to test whether new drugs are likely to be addictive. Government must do their own tests for cross-dependency between any new psychotropic drug and all known drugs of addiction and restrict any rogue drugs that turn up. Genuinely new families of drugs must be tested at various dosages over long periods of time.

Measures on either the doctors' or the drug houses' side of the medical-industrial complex are unlikely to have long-term effects on the whole any more than persuading one Siamese twin to give up booze and fags is likely to help the conjoined pair if the other twin is on Halcion. Simultaneously with increased and strengthened regulation, universities and professional associations must work to restore healing to medicine so that doctors do not need knockout drops for wastepaper basket patients. Medicos must either learn pharmacology or hand over the responsibility for prescribing to pharmacists.

The short-treatment, human potential therapists tend to block self-indulgent emoting with a view to effecting behavioural change. They offer this dictum: 'Don't say "you're sorry-say you won't do it again!' And that is the message that consumers should send to government, drug houses and doctors.

#### **NOTES**

#### **PREFACE - A WORLD SPLIT OPEN**

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## **CHAPTER I - SCRIM**

- 1. When I wrote this, I believed it to be true. Now I think BZD probably did not cause my menorrhagia. See Ch. 7.
- 2. This is true. However, there is reason to believe that BZDs also depress the immune system. This is currently being investigated Ms. Helen Jarvis in the Physiology Department of Monash University. ANON 'Tranquilliser Addicts in First Health Study,' *Montage*, September 1992, p. 4.
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#### **GLOSSARY**

#### acute

sudden onset; cf. chronic

## advertising

commercial messages in words or pictures aimed frankly at selling products or services; e.g. a picture of track shoes with accompanying words either in print or on television; cf. promotion, public relations

# agnosia

loss of capacity to understand words

## agoraphobia

fear of open or public spaces; cf. claustrophobia

## anaclitic depression

depression in babies caused by loss of primary caretaker or love object

# antagonist

a drug that prevents a neurotransmitter acting on a neuroreceptor; cf. neurotransmitters, neuroreceptors

# antihyperthyroid

substance that corrects an overactive thyroid gland

# anxiolytic

substance to reduce emotional arousal - generally identified with anxiety; cf. hypnotic, sedative

# aphasia

speech disorder resulting from damage to the cortex cf. disarthia

#### ataxia

loss of co-ordination

# behavior therapy

non-drug therapy derived from Pavlov's research into conditioning; employs desensitisation, reinforcement and aversion (reward and punishment)

#### biofeedback

related to behavior therapy; entails measuring a bodily symptom such as electro-galvanic skin resistance, blood pressure or penile engorgement, and teaching the patient to control it e.g. by turning off a buzzer or bell

## bribery

giving rewards beyond those allowed by law to entice a person with a duty of trust to pervert, corrupt or compromise that trust; cf extortion

#### bronchi

the thicker tubes in the tree-like structure of the lungs

#### bronchiectasis

scarring and thickening of the bronchi

#### chronic

long-term; cf. acute

#### cilia

hairlike filters inside the lungs

# claustrophobia

fear of confined spaces; cf agoraphobia

#### **Cnidian medicine**

reductionism tradition of medicine originating on the peninsula of Cnidus; emphasizes the disease more than the patient; Cf. Coan

#### Coan medicine

holistic tradition of medicine originating with the teachings of Hippocrates on the island of Cos around 460 BC; emphasizes the patient more than the disease. *cf. Cnidian* 

## cognitive therapy

non-drug therapy; uses the nexus between thinking and feeling to establish rational control over emotions and conduct

## congenes

belonging to the same kind or class

#### cordon sanitaire

a disease-free area established by systematic use of quarantine around the periphery

#### cortex

the outer layer of any organ; when used alone, it usually refers to the outer layer of the brain (cerebral cortex)

### cremasteric reflex

an involuntary nerve circuit that tightens the scrotum and pulls the testicles closer to the body when danger threatens

#### crentinism

form of physical and mental retardation occurring in children due to thyroid deficiency; rarely seen nowadays due to the use of iodine to supplement diet

#### cross-tolerance

a second drug cures the withdrawal symptoms of another but is just as addictive

### disarthia

speech difficulty arising from the mouth and tongue cf. aphasia

## endocrines

ductless glands that discharge their secretions directly into the bloodstream *cf hypothalamus, limbic system* 

## endogenous

originating within the organism

## endoscopy

instrument using optical fibre technology for looking into the body without opening it up surgically

## epidemic

sudden widespread outbreak of disease cf pandemic

## epidemiology

study of the patterns of disease occurrence

## epidiectic display

non-verbal communication between males for the purpose of establishing dominance

## epigamic display

non-verbal communication from one sex to another for the purposes of mating; courtship display

## extortion

soliciting a bribe - usually with duress; cf. bribery

## grease payment

incentives to get bureaucrats to do the job they are paid for; inducements to doctors to fudge research results or prescribe one firm's products; *cf extortion, bribery* 

## gynaecomastia

excessive growth of breasts in males

#### half-life

the time required for the concentration of a drug in the body to fall to half its original amount

# hyperacuisis

bizarre and painful oversensitivity to sensory stimuli: light, sound, smell, touch, temperature, taste

# hypnotic

substance that reduces emotional arousal to the point where sleep occurs - a strong, or stronger dose of *sedative or anxiolytic q.v.* 

# hypothalamus

a segment of the brain controlling survival mechanisms such as thirst, appetite and temperature; also controls survival behavior such as fight, flight, feeding and mating; secretes hormones into the pituitary gland and so controls the endocrines; *cf. limbic system, endocrines* 

# hypothermia

low body temperature due to disease or cold

# hypotonia

abnormally low muscle tone or strength

# iatragenic

caused medically

## kypho-scoliosis

permanent sideways and backwards twist of the spine; *cf. scoliosis* 

## **Korsakov's syndrome**

loss of memory for immediately recent events due to alcoholic degeneration of the brain; memory of the distant past remains

## limbic system

often called the mid-brain; composed of several structures; sometimes called the hot brain because it handles coarse emotions such as anger, fear, and sexual arousal; also controls smell

#### loss leader

product sold at a loss in order to attract customers who will buy other products

## market segmentation

breaking up a population of potential buyers into smaller groups according to age, marital status, socioeconomic status, geographical distribution etc. with a view to targeting products more precisely at a likely market

# menorrhagia

prolonged and heavy menstruation

## mlieu interieur

the internal environment of the body

# neuroreceptors

specific sites on the membrane of nerve cells that respond to appropriate chemicals - the neurotransmitters cf. neurotransmitters, antagonist

#### neurotransmitters

chemical messengers between nerves; *cf. antagonist, neuroreceptors* 

# nystagmus

involuntary jerky movements of the eyes

#### Occam 's razor

a principle of logic stating that, if several equally plausible explanations are available for a phenomenon, the simplest explanation is to be preferred

### old brain

the hypothalamus q.v.

## pandemic

sustained widespread occurrence of disease cf. epidemic

## peripheral neuritis

inflammation of the nerves linking the brain and spinal cord to the organs, skin and other parts of the body

## placebo

a substance that has no action of its own but stimulates the mind/body to respond positively as if it were responding to a cure

## polydipsia

abnormal copious drinking

# polyuria

abnormal copious urination

# promotion

activities to promote sales of products or services involving more complex messages than words or pictures e.g. giveaways, free samples, demonstrations etc.; e.g. Olympic athletes signing autographs on track shoes for purchasers; *cf. advertising public relations* 

# proprioception

the automatic, continuous but unconscious sensory flow from muscles, tendons, joints by which their position, tone and motion is continually monitored and adjusted, permitting us to move through our environment

## pruritis

itching

## pseudomonm

bacterium causing various diseases in humans and animals; exists in resistant strains

## public relatons

discreet ways of bringing goods or services to public notice without simple advertising messages e.g. when the manufacturers of track shoes donate money to an appeal to send athletes to the Olympics, the donation is reported as an unpaid news item; *cf. advertising, promotions* 

## pyridoxine

vitamin B6; in excessive doses causes loss of proprioceptive capacity; *cf. proprioception* 

## quadriceps

the large, four-headed muscle of the thigh which extends or straightens the knee

## scoliosis

permanent sideways twist of the spine; cf kypho-scoliosis

#### sedative

synonymous with anxiolytic but no longer fashionable; cf. anxiolytic, hypnotic

#### somatic

physical, of the body

# standardised assessment of causality (SAC)

a series of if/then questions to show whether a suspected adverse drug reaction is actually caused by the drug under suspicion

#### status asthmaticus

an asthma attack so prolonged that it is a semi permanent condition

# tardive dyskinaesia

involuntary, repetitive tics of the mouth and face, body and limbs; may be a feature of old age or may be a result of antipsychotic medication

#### tolerance

after repeated doses of a drug, the same quantity produces reduced effect or none at all; dosage must be increased to get the same effect as the original amount

#### torts

law of civil wrongs including injuries due to breach of duty, negligence, nuisance and defamation

# **Tourette syndrome**

disorder of the emotions characterised by speediness, overenergetic tics, jerks, mannerisms, fantasies, and playfulness

### transient ischaemic attack

small stroke; usually due to temporary compression or spasm of a blood vessel

## trichotillomania

an obsessive-compulsive disorder which forces the sufferer to pull strands of hair out by the roots until s/he is bald

# unique sales proposition

a difference between essentially similar products fabricated by marketers to persuade buyers that they are getting a unique product

# variance payment

a bribe