

BEFORE THE LIGHT DIES.

By

Gurli Bagnall

Do not go gentle into that good night.

Rage, rage against the dying of the light.

Dylan Thomas

It had not been my intention to post this article at this time, but I changed my mind when I was recently taken to task by a person who presented himself as an M.E. advocate. My approach to a questionable issue was too outspoken for his liking and judging by his comments, anyone campaigning for patients' rights must always turn the other cheek and defer to the Drs. God - as he has apparently been doing for the past twenty years. To challenge their expertise and ethics, is to incur their wrath and to incur their wrath, he said, is tantamount to throwing the baby out with the bath water.

My question to him was: How much is it reasonable to take, before taking it becomes unreasonable?

On a personal level, a great deal has happened during the past couple of years, and during some of the darker hours, I began to mentally prepare myself for taking a step which I felt might one day become necessary. (1)

Choking on anger is no way to die. I needed to write about it, but it was hard. I didn't know where to start, and as time marched on, I feared my demise might occur before I actually got anything down on paper. But then I realized that much of what I wanted to say has already been said - and said repeatedly by others with a greater knowledge than I. That leaves me with only my personal situation and feelings to clarify.

For decades, those in my situation have either been dismissed or told in terms that can hardly be described as flattering, that they are nut cases. If we have any concern for our children and grandchildren, the medical “So what?” attitude is one we can no longer afford to accept without strong protest. It is hard to campaign when your health and financial status have been destroyed, but on an international level, there are millions of us and one would hope that the sheer weight of numbers will ultimately have an effect.

There are no profits in cures, but there are in controlling (or claiming to control) symptoms. Researchers have still not found the cause of cancer but how much of a mystery can it be when the same researchers are able to induce the disease in laboratory animals? And how about the ongoing controversy over AIDS?

“The irruption of lay expertise had a surprising impact in the domain of therapeutics. Initially the activists’ complaints were simple: treatment was too little, too late - get ‘drugs into bodies’ was the campaign slogan. But users’ lobbies delved deeper: was the preferred AZT (azidothymidine) effective (as prophylactic or treatment)? Or was AZT as others claimed, ‘AIDS by prescription?’” (“The Greatest Benefit to Mankind” Roy Porter. Page 708)

With the production of more and more psychiatric drugs, each supposedly better than the last, mental disorders should now only be found in the history books. But they are not. Far from it. We now have an epidemic of psychiatric illnesses such as we have never seen before.

And what about ME? What about the Gulf War Syndrome? Given that the mountain of evidence pointing to these being organic diseases is ignored, and given that the victims of them are swept under the psychiatric carpet to be stomped on, you do not need to be a rocket scientist to realize that there is a massive cover-up afoot.

It boils down to the fact that, despite the billions thrown at research every year, medical science has barely scratched the surface of disease. So who benefits from those billions?

GPs are not generally engaged in laboratory research so their ignorance in some instances, is understandable. Devastating though that is for the patient, it is not the main problem. The main problem is attitude. There must be a book of rules somewhere intended for doctors’ eyes only and judging by common behaviour, the opening page must be along the following lines:

RULE ONE: Never admit to ignorance. It destroys the profession's mystique and the public's perception of its infallibility. Instead, blame the patient for his own misfortune (malingering, inadequate personality, neurotic etc.). If he becomes a "fat folder" patient and falls into the "heart sink" category, (a) diagnose him with a mental disorder and stuff him full of psychotropic drugs or (b) refer him to a psychiatrist who will diagnose a mental disorder and stuff him full of psychotropic drugs.

RULE TWO: If the patient seeks help from an alternative therapist, emphasize that such people are charlatans. Tell him he is wasting his money and to make sure there is no misunderstanding, do not be afraid to ridicule the patient for his naiveté. Remember, it is important to keep the revenue flowing into YOUR practice.

RULE THREE: If medical science discovers a physical reason for the condition the patient suffers, never apologize for the years of pain he has endured, nor the large sums of money he has paid in fees to your practice. That would (a) reflect badly upon the profession, and (b) the patient might ask for a refund.

RULE FOUR: Similarly, should an alternative therapist discover a physical cause for the patient's condition, never apologize for your mistake. Do not show an interest in that condition, the method by which it was discovered nor the cure. Adopt a dismissive attitude. It is time to accept that the patient has served his purpose. He has already contributed considerably to the income of your practice, and there will be no more golden eggs from that particular goose.

Whistleblowers within the medical profession are almost without exception targeted by their colleagues and retribution can be swift and ugly. Losing careers due to trumped up charges, is not new. As a result, when doctors disagree with entrenched policies, it is only the very brave who speak out. One of our heroes is Professor Malcolm Hooper who has withstood threats from the "best" in the business.

Practitioners who go quietly about their business according to the dictates of their own consciences, sometimes feel the wrath of their colleagues as well. I am therefore particularly grateful to the two or three doctors I came across during the course of my illness who treated me with kindness. One of them is my current GP who visits two to four times a month to administer acupuncture. We have had many good laughs together. But he is one of the exceptions, and the struggle for survival did not start eighteen months ago.

My struggle has been ongoing for 30 years. The first fourteen consisted of repeated misdiagnoses of a trivial matter which a competent doctor could have sorted out with appropriate treatment in a matter of two or three weeks. Instead, inappropriate treatment resulted in iatrogenic disease including addiction. As my health deteriorated, my confusion increased and medical attitudes became unpleasant, demeaning and abusive. Every new

doctor I consulted must have known why I was so ill, but each of them simply carried on where the last one left off.

When it finally dawned that it was they who were making me sick, it was too late. The damage was done. The aftermath was the neurological condition, Myalgic Encephalomyelitis, and it has been with me for the last sixteen years.

Rational thought returned once I was off the drugs and being financially ruined, I realized that unless some sort of compensation was awarded, I would lose my home and belongings. Thus began the disillusionment to which so many have been subjected. Those who suffer the adverse effects of prescribed drugs or other medical inventions; those who have been infected with HIV or Hepatitis through prescribed blood products; families and friends who have lost loved ones due to medical “error”, all know what I am talking about. They, like me, found that the democratic societies in which we live, are a total sham. The concern is not for the injured party, the loyal voter, but rather for the culpable corporations and the authorities who conspire with them.

In his new book “Brave New World of Zero Risk: Covert strategy in British Science Policy”, Martin Walker describes the scene as it was in the UK. It was identical to the scene in New Zealand in the 1980s and 1990s:

“On the fringes of parliament, industry, democracy, health care were bought and sold by an army of consultants, PR reps, multinational corporations, odd-jobbers and spivs. The Arthur Dalys of Oxford and Cambridge and the Del Boys of the new concrete campuses, the hard-hearted, go-getting Thatcherites who had taken in individualism with their mothers’ powdered milk, came to feed on the remaining carrion of public service in Westminster and Whitehall.... Why make bones about it? The multinationals wanted to sit with the Government on the front benches...”

In the event of accidents or medical misadventure, the only avenue for compensation available to New Zealand citizens, is through the compulsory state operated, tax-payer funded, Accident Compensation Corporation (ACC). Typically, the medical personnel who were commissioned to advise the ACC, deliberately misinterpreted my medical records. They “re-categorized” the drugs and falsely declared their recommended uses and doses, and without seeing or speaking to me, they deemed me to be a complete mental case. From the “professional” point of view, writing reports of this nature was and continues to be, a profitable business - and not only for those who write them, but also for the staff of the ACC who, it has been reported, receive generous bonuses for successful rejections of legitimate claims.

The fraudulent practices of the ACC, have been the repeated subject of media reports for the past twenty years. The lack of political will to intervene, leaves no doubt about the complicity that exists.

When I discovered that sworn evidence had been destroyed and my complaints in this regard were ignored, I threatened to place my entire file at the disposal of the media. This brought about an immediate reversal of the rejection of my claim for compensation. But even then, the struggle did not stop. Attempts were constantly made to “prove” I had recovered and was no longer in need of support.

I give as an example the following incident because the medical “assessment” was carried out by a high-profile, self-professed ME specialist commissioned by the ACC to (quoting from an internal memo) “disentitle the claimant”. The strategy was described and the “specialist” followed through with much enthusiasm. She rubbished the result of the blood test carried out at the University of Otago by Les Simpson, even though she still used the same test for her private patients. (Confirmed in writing by Simpson and dismissed as irrelevant by the ACC.) She did not discuss her proposed recommendations with me thereby placing my life at considerable risk. Amongst the drugs she suggested, was HRT for she stated that my problems stemmed mainly from age. Unable to tackle stairs or walk more than a few metres, I had to battle hard to avoid being subjected to her proposed rehabilitation programme and since I lived on my own and found it difficult to turn over and sit up in bed, my request for a hospital bed was rejected on her advice. It would encourage me, she said, to lie about all day. Glaringly, she neglected to mention in her report such findings as a sub-normal temperature.

Perhaps the most distasteful part was when the physical assessment was over. Who, she asked, would pay for her services? Since the ACC had demanded the assessment, payment was their concern and the question momentarily confused me. Getting no immediate reply, she said, “Oh yes, of course, ACC will pay.”

Given all that happened, I am in no doubt that had I offered to pay the fee (which I could not afford) the report would have gone in my favour. As it was, I spent the next seven months battling the determined efforts of the ACC to “disentitle” me on the strength of this “specialist’s” assessment.

My feelings about this person are hard to describe for she is revered in certain circles as the guru of ME. As for the hospital bed, I was forced to sell precious family items, part of my daughter’s legacy, to fund it myself.

How much did these never-ending battles contribute to the deterioration of my health, and how well, I have wondered, would the perpetrators, the medical deniers, liars, bullies, abusers and criminals have handled it? People of this ilk tend to become craven cowards when faced with their own medicine; to borrow a rather unlovely Afrikaans expression, I suspect there would be “snot and tears” in all directions.

Like most of us, I have given of my best and more in dealing with these circumstances. Even during the medical crises that arose, I quickly learnt to remain calm. If one is dealing with the situation alone (often the safest way), calmness is crucial to survival. When the medical profession is involved, an ME sufferer cannot afford to show distress or fear for such emotions are (mis)interpreted as mental disorders.

For more years than I care to remember, I have spent twenty hours of the day on average, on my bed. I have progressed from being able to care for myself, to needing home help, to having to support myself against walls and furniture, to crutches, and now to a motorized

wheelchair. And all to the accompaniment of the “evidence-based, best practice” serenade, sung with gusto but with remarkable lack of talent.

As an ex-teacher, it never ceases to amaze me that the medical profession harbours so many members who must surely be amongst the slowest learners of any group within society. Either that, or they are completely lacking in conscience and ethics for they deliberately disregard the traumas that were caused by past mistakes; sick people pay the price as those “mistakes” are repeated over and over again. An example of this was recently highlighted when two Australians, Robin Warren and Barry Marshall, were awarded the Nobel Prize in medicine for their discovery that peptic ulcers are caused most commonly by the treatable bacterium, *Helicobacter Pylori*. *“This was very much against prevailing knowledge and dogma because it was thought that peptic ulcer disease was the result of stress and lifestyle”* (USA TODAY (03/10/05); a diplomatic way of saying that the discovery was, in general, not welcomed by the medical profession.

Shamefully, the unnecessary suffering, the disruption to the patient’s life, the unpleasant diet, the peritonitis and the surgical procedures associated with psychiatric labeling, were not a consideration. *Helicobacter Pylori* rocked the boat of those who benefited financially from treating ulcers as a mental disorder. Income from regular appointments, surgical procedures and medical interventions which were useless at best and dangerous at worst, ceased. (RULE THREE: If medical science discovers a physical reason for the condition the patient suffers, never apologize for the years of pain he has endured, nor the large sums of money he has paid in fees to your practice. That would (a) reflect badly upon the profession, and (b) the patient might ask for a refund.)

Most ME sufferers will understand how those who lived with peptic ulcers must have felt about the never-ending and insulting lectures they received regarding the inadequacies of their personalities.

Can it be that a career in medicine attracts people with a natural talent for insulting others, or is the art of insulting included in the medical curriculum?

In my own situation and at this stage, it is no longer physically possible to “run” on empty and reluctantly, I must accept the ambitions that remain for what they have become - pipe dreams. It would take a few years of reasonable health to realize them.

Like a number of other ME sufferers, I have succumbed to heart failure, a complication of ME which I believe is directly related to years of medical neglect and abuse. My condition is terminal but at this point, I have outlived the specialist’s expectations by about a year. I am

therefore conscious of the fact that, contrary to his belief, the “time-table” is not set in concrete and I need a contingency plan.

Wessely School psychiatrists have built their careers and reputations on denying the physical nature of ME/CFS, with the result that untold numbers of chronically and seriously ill patients are bullied, derided, threatened and driven to suicide and being told they are not physically ill but are suffering from “aberrant illness beliefs”. (The Mental Health Movement: Persecution of Patients? Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, University of Sunderland. In collaboration with members of the ME community.)

In these circumstances, there is only one option. It is not what I would choose if I HAD a choice. But I do not. The choice was imposed upon me by others; others who publicly express shock and indignation when debating the subject of voluntary euthanasia and who have the gall to proclaim: “We’re here to SAVE lives! NOT to kill people off!”

If this ultimate step becomes necessary, it has to be taken while I am still able to carry it out. I will not wait until I am completely defenceless and at the mercy of “health professionals” in a residential facility – “health professionals” who dismiss ME as a mere state of mind and who, given my physical inability to resist, will force me to take drugs that will add to the distress.

The psychobabble brigade will call this act suicide and explain that the cause of it is depression. It does not matter that they did not know me nor anything about me. After all, they are the “experts” - so they tell us. For some of these “experts”, the diagnosis is a matter of expedience; those who actually believe it, lack the basic empathy and acumen to see beyond it. But then ironically, apart from the exceptional few, psychiatrists have little understanding of the human condition.

The truth of the matter of course, is that in these circumstances, it is rarely suicide. It is murder resulting from the malignant influences of people who hounded us to our death. Should my circumstances reach this stage, it is they who will metaphorically press the lethal instrument into my hand and guide it.

In the ME world, when patients refuse to accept medical opinions that are hazardous to their health, the reactions are predictable. The rapid responses in the electronic British Medical Journal following articles on medical error provide some fine examples of professional arrogance and outrage; the authors seem not to be aware that respect must be earned; that the letters after their names do not automatically award it. But tantrums, while they may intimidate, are generally not persuasive. And persuasion is the main tool when engaging in conflicts of interest.

UK psychiatrist, Michael Sharpe, came up with a novel answer to patient resistance to hazardous medical opinions. He claims it is a defining sign/symptom of mental disorder.

“The majority of patients with Chronic Fatigue Syndrome [ME] have no doubt how they prefer their condition to be seen. Indeed the vehemence with which many patients insist that their illness is medical rather [than one with a] psychiatric basis

has become one of the accepted hallmarks of the condition.” (From lecture notes entitled “ME – What do we know?” Co-cure, 31 August, 2005).

The convenience of this as an excuse to dismiss criticism is clear. If it were not for personal gain (conflicts of interest), one might logically attribute the attitude to a grossly over-developed sense of superiority and omnipotence - symptoms which are included in the Diagnostic Statistical Manual on Mental Disorders (DSM), which is compiled by the profession itself.

By the “we”, Sharpe referred to the self-professed experts from the Wessely school of thought on what they call chronic fatigue syndrome. These “experts” have been and still are aggressive participants in the stampede associated with the current “gold rush”.

The current “gold rush” commenced when the pharmaceutical industry started to churn out psychotropic substances by the ton. Psychiatry staked, and continues to stake, claims in as many disorders as it could and can commandeer or invent. The proof of this appears in the aforementioned DSM which gets obscenely fatter with each update.

The main difference between the old and the new version of the gold rush, is that the new version has generated wealth such as the old timers never dreamed existed.

“Over the past 50 years, there has been an astonishing increase in severe mental illness in the United States. The percentage of Americans disabled by mental illness has increased fivefold since 1955, when Thorazine - remembered today as psychiatry’s first ‘wonder’ drug – was introduced into the market. The number of Americans disabled by mental illness has nearly doubled since 1987, when Prozac - the first in a second generation of wonder drugs for mental illness - was introduced. There are now nearly 6 million Americans disabled by mental illness, and this number increases by more than 400 people each day. A review of the scientific literature reveals that it is our drug-based paradigm of care that is fueling this epidemic. The drugs increase the likelihood that a person will become chronically ill, and induce new and more severe psychiatric symptoms in a significant percentage of patients.” (Anatomy of an Epidemic: “Psychiatric Drugs and the Astonishing Rise of Mental Illness in America.” Robert Whitaker - Cambridge, MA. Published in: Ethical Human Psychology and Psychiatry, Volume 7, Number 1, Spring 2005)

(I draw attention in particular to the last two sentences.)

In case there are still some who are not convinced about the seriousness of the situation, consider the above quote alongside the current Bush Administration’s drive to test all US citizens for mental disorders and the prescribing of specific drugs where “needed.”
(2,3,4,5,6,7,8,9,10,11,12,13,14)

Consider too, that the initial stages of this programme is aimed at school children. A child may be brilliant in literature and art, but hopeless at maths. Nothing abnormal in that one might say, but not so. S/he “suffers” from Developmental Arithmetic Disorder which will be treated with one or more toxic, mind-altering and addictive substances. If (a) the child protests at being thus labeled, he will also be diagnosed with Oppositional Defiance Disorder and (b) if he refuses outright to take the prescribed “medication”, he will be deemed to suffer from Noncompliance With Treatment Disorder.

Every angle is covered. Psychiatry has become a two headed penny. Flip the coin, and it will show you are either a mental case or you are...well...a mental case!

Sharpe has become well known for his pronouncements. One for which he is particularly reviled states: *“Those who cannot be fitted into the scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service.”* (15) He was of course, referring to ME.

That Sharpe et al influence many within the profession is true. Doctors who feel sorely inconvenienced by sick people, have no shame or guilt in using the Wessely school “logic” to dismiss and demean. However, the “arguments” (which include a never ending stream of newly invented and meaningless jargon), do not impress all. Speaking at a two day conference held at the Novartis (pharmaceutical company) Foundation in London in October, 2002, Sharpe’s colleague, (UK) Professor Trudie Chalder, had that dilemma covered.

“Rather than start with the physicians which might be quite a difficult task, we could make a start with youngsters in schools. My experience is that they are much easier to educate. The only barrier is the parents. Once we have the child on our side we are in a very good position.”

http://www.meactionuk.org.uk/PROOF_POSTIVE.htm

With these few words, Chalder highlighted a number of questions regarding her profession’s modus operandi. Lack of credibility and ethics as well as deception are high on the list; in this instance, manipulation and exploitation of impressionable children and inciting those children to rebel against their parents, can be added.

Hard to ignore, is the mental image of power-hungry psychiatrists, standing on the sidelines and rubbing their hands in glee as they smugly observe the mayhem they have unleashed upon a confused society. It is not outrageous to suggest that this might be how mass hysteria was invented.

Psychiatry has become known for its wide use of “diagnostic” questionnaires which indicate

for example, that if a headache or sore back is experienced, then the subject has a mental disorder. Just as Wessely et al present these results as scientific evidence, so they would clearly have us believe that unconscionable strategies such as Chalder recommended are both legitimate and scientific. The contempt held for the lay community could not be demonstrated more clearly.

Conflicts of interest are the driving force behind the followers of the Wessely school. The game in which they have a stake, whether it be directly or indirectly, is about power, status and money.

It is ironic that even as these “experts” benefit from their own conflicts of interest, they accuse ME sufferers of wanting to benefit from the sick role. After 30 years, I have learnt a great deal about financial hardship, but have yet to discover the benefits. Indeed as the “experts” dine on pheasant and caviar, ME sufferers are lucky if they have dripping to go with their bread.

Over the years, and contrary to all I once believed, one glaring fact has emerged: a career in medicine and in particular psychiatry, offers protection to the incompetent and to those with sadistic and criminal tendencies. People of this ilk misuse their power to denigrate the intelligence and integrity of others; to deliberately cause harm; and to deny ill people the essential assistance they need to survive.

“Intellectual property” is a term I first heard at the time the medical profession was striving for the right to maintain ownership and control over their patients’ records. These records, it was said, were their private thoughts and as such, belonged to them.

Their clients saw it differently for it is within the records that misdiagnoses and inappropriate treatments are listed, and where otherwise unexplained damage can be seen to have resulted from unjustifiable judgmental attitudes.

At this stage of my life, I have nothing left to lose. The scavengers and parasites have left me little in the material sense to pass on to my daughter. All that remains is my intellectual property. My words.

I hope in some small way they will contribute to a safer future but at the very least, my daughter will know that her mother did not bow down to pressure to be silent; to turn the other cheek. That while there was still light, she looked the world in the eye and continued to rage.

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