

Friday, June 3, 2005

Submission to the Senate Committee on Mental Health

This is a personal submission and I request that my name not be published.

As a person with a mental illness I stress that I am a vulnerable person and have been marginalised by my illness in a way that cannot be imagined by a well person who has not experienced such an illness. I am putting in this submission, now that I am a little better than I was, because I want to counter the weight of all those professional submissions from professional associations and tell it how it is from the point of view of a sick person.

Somebody should be asking people such as myself, what can be best done to help now and what went wrong that you became so ill? Therefore I am putting myself forward.

My JOB/My FINANCES

I live in near poverty and have been saved from homelessness by the actions of a kind friend who has taken me in. I have been ill with bipolar disorder for 32 years now, since I was seventeen years old, but it is only the last ten or twelve years that I have been so devastatingly ill that it has taken over my life. I fear for my future unless I can somehow win this battle.

For much of the last twelve years I have been so ill, I could not manage my finances or my life. I lost my home and my job. I have lost many friends simply because I cannot afford to go out with them anymore and can afford few recreational activities. It has been loss after loss after loss. I did the most strange and devastating things while manic, (such as buy a house at an auction, on impulse).

I am an intelligent person with postgraduate qualifications and a history of achievement but am currently finding it difficult to achieve satisfactory employment. I am surviving by doing casual teaching but I currently live in the country and there is only limited and irregular work available. I am currently trying to negotiate the red tape of Centrelink to try to gain some support under NEIS so I can become self-employed. I have much talent, but I do not function well in some respects (memory, concentration especially). Mid-life career change is not easy for anyone, but if you have a mental illness it is terrible. Before I became ill, I was an educational psychologist, I am also a trained maths teacher, but because of what has happened, I am looking at moving in a totally different direction.

When you are as sick as I have been, dealing with Centrelink is so difficult that I tried and gave up several times. I probably would have been eligible for Healthcare card etc. I was so sick I couldn't cope with their procedures or fill in the forms. At one stage I was given a thirty-page form to fill in. Before I became sick, I had income-insurance, but in the end I lost that also because I was in such a drug induced fug (all legally prescribed prescription drugs) that I was too sick to keep filling in the forms.

My FAMILY

Some people may have the support of their family who could help them, but the government cannot assume this. Many people with these illnesses have been abused and hurt by members of their own family. My own parents have been awful. They have always been extremely authoritarian and do not know how to be supportive or kind. They never did. I grew up under a harsh repressive type of regime. They are manipulative and bullies. They simply could not understand that I was too sick to do simple things. They knew me as a competent intelligent person. They thought I was being lazy and stupid. They thought they could sort me out by criticising, nagging, complaining and punishing. In the end, I was so fragile I couldn't take it anymore. I was too anxious to answer the phone because it was probably my mother ringing up to complain about something. In the end I told my parents I never wanted to see them again. I just needed some quiet in my head. Five years later I still have nightmares in which I wake up to hear my mother's loud and complaining voice going around and around in my head. She complained about the most trivial and stupid of things. She offered bucket loads of absolutely impossible advice and then was affronted when I did not follow it and complained endlessly about that. I was just too sick and too fragile to deal with her.

My mother is a churchgoer of the old-fashioned kind. I am sure she believes that my illness is caused through moral weakness. She apparently believed that if she punished me enough, complained, nagged, bullied, and whined that my bipolar disorder would go away. When I eventually did end up briefly in hospital, she refused to bring me a book or magazine and even resorted to telling lies to try to make me feel guilty. She was extraordinarily cruel. She does not realise how lucky she is that I have never had an alcohol or drug problem, never been in trouble with the law or any of the other things that often happen to people with severe bipolar disorder.

My mother knows what is socially acceptable and would brag about all she was doing to be helpful in front of other people: her punishments were behind the scenes sneaky and nasty. The rest of the family would not believe most of what she did. There is a lot of stigma associated with mental illness and I think my mother believed I was deliberately bringing shame on the family by having the audacity to be mentally ill. One day if I am well, I will go back and deal with her, but up until now I have been too sick.

I never knew quite how awful she was until I became sick. I guess a mental illness causes you to find out things about other people that you would otherwise never know. There have been no services that I could find that could help me deal with her.

PSYCHIATRISTS

I particularly wish to comment on my experiences with doctors, psychiatrists and prescribed psychiatric medication. If my experiences are common and I think they are, then there should be a Royal Commission into the activities of psychiatrists and the prescription of psychiatric drugs. Psychiatric patients are vulnerable and psychiatrists are not sufficiently accountable for their activities.

Psychiatrists are different to other doctors. I didn't realise that until I was a long way down the track so I was not forewarned or prepared to deal with them.

Most doctors are highly trained in a scientific discipline and your treatment will be based on science. Your illness will be diagnosed with assistance from pathology tests and X-rays ETC. The treatment will be straightforward enough, once an accurate diagnosis is made.

In comparison to this, psychiatrists are witchdoctors. Psychiatry is a rough and ready art indeed. Psychiatrists are trained as doctors, but somewhere they go off the rails.

People who go to psychiatrists are often at their most vulnerable and because of the stigma attached to mental illness, they may not talk to other people about what is happening and that makes them even more vulnerable.

There are no objective tests for diagnosis and the symptoms vary widely between individuals. Your doctor may or may not be observant and skilled enough to get the diagnosis right first up. In the case of bipolar disorder the typical diagnosis takes more than ten years. In my case it was much longer.

I had complained to my GPs several times over the years about bouts of depression and other symptoms but in the end these episodes tended to resolve themselves. I was referred to a psychiatrist several times, but usually by the time I got there the symptoms resolved themselves. I didn't link these episodes and did not realise the true extent of the symptoms. I am sure I was hypermanic (a lesser form of mania) at some stages, but never myself recognised it as part of an illness. In the end I was driven to a psychiatrist by extreme and worsening anxiety and from there on in, the situation went down hill.

Some medications work for some people, some do not. The doctor will experiment in order to find a medication or combination of medications that might work for you.

If you do not respond to a small dose of a drug, the dosage will be pushed higher and higher. The side effects of these drugs are frightening, even in small doses. The side effects of high doses are terrifyingly awful, particularly if you happen to be given a combination that backfires. You may even be poisoned by such a high dose that you cannot walk as I was.

If you are lucky, I suppose, then you get the right diagnosis and treatment straight away. If you are not, then you might be launched onto the most terrifying treadmill over which you no longer have any control. You become so sick that you don't know if you are Arthur or Martha. You don't know where to go for help and even if you do ask over and over, no one knows what to do. You get pushed around all over the place.

In my own case, antidepressant drugs and even a common benzodiazepine launched me into severe and prolonged periods of manic psychosis. I had long periods of mania lasting over three months at a time. I didn't know I was manic. Manic feels good at first. The

psychiatrists could not apparently see I was manic and off I would go to do things that were disastrous for my welfare. Eventually I would crash and I would see that I had been manic. I would be mortified and horrified and then sink into an even worse depression, for which I would be given more antidepressant drugs and the cycle would start again. I was totally out of control internally. Outwardly it is astonishing that I managed to last so well for so long.

I'm quite happy to come in and tell the senate committee of some of the saga and how it developed. It was like a small bushfire that developed into an out of control inferno. It is an amazing story and yet if you met me, you would think I was a very quiet, ordinary sort of a person. Everything that happened will be somehow documented in my medical records.

Actually, I think that is part of the problem. Had I been a little more extraverted and flamboyant to start off with, I would probably have acted out to the extent that I alarmed my friends or family or caught the attention of police, or have somehow ended up injured in hospital, but because I am normally, polite, well behaved disciplined and restrained, most of my manic behaviour was not so outwardly over the top that it wasn't obvious. In addition to that, I was an independent person who lived alone. A housemate may have noticed.

It took five severe episodes before lithium was prescribed. By that time I was absolutely exhausted and depleted in many ways. In the past, people died of exhaustion. I was very nearly there. This absolutely should not have happened in this day and age but it did. For various reasons I changed psychiatrists, but I have never really found one who is satisfactory. If I am recovering now, it is in spite of their treatment.

These psychiatrists knew that mania was a possible side effect of many anti-depressant drugs but they weren't apparently on the alert for it, and they apparently did not know how to recognise it, or what questions to ask. Even after I crashed, they had no idea how to deal with the aftermath, or how to deal with the devastation caused except to write more prescriptions. To temporarily lose your mind to a psychosis is an awful thing, and after it has happened several times, then you are left in a position of extreme horror, because you no longer believe that anything is safe. You can no longer trust yourself and your own sanity. The ground can no longer be relied upon to be solid.

Eventually, a psychologist, whom I had temporary access to, taught me how to recognise the initial signs of mania and I was then able to take action to protect myself as soon as I recognised the early signs. Psychiatrists do not have sufficient counselling and talking skills to be able to do this, but it was the most important thing that happened and if it had not happened, I am quite sure I would be dead now, one way or another.

Psychiatrists should have this knowledge, or at the very least be able to refer their patient to someone who would help.

Even so, this was not enough to help me recover from the trauma of all that mania and I am still slowly recovering and trying to get my life and myself back in order. I moved to a country town, I have the service of a psychiatrist and eventually found some medication that helps, but it is not enough. I need some assistance and support to get properly back in the workforce. I would like the support of a trained counsellor to help me deal with my mother and also to help me get over the entire trauma.

The psychiatrist prescribes drugs, but he doesn't help with any of the day-to-day problems. In any case I can't afford to go near him very often because he charges enormous fees over and above the Medicare rebate. This man has never bothered to take a proper history. He is pretty lazy and I am sure if I had not cranked up a fuss, he would still have me on lithium, which is only of marginal benefit to me. Worse than that, the only drug that has helped, Lamictal, is not on the subsidised pharmaceutical benefits list and is very expensive. I go to this psychiatrist because I have no choice.

The local GP has nothing better to suggest. The services of the state mental health team are not accessible to me because I am not judged sick enough. I present well apparently.

Without money there is no quality of life. For example, I haven't been to a dentist for six years and had to put up with months of toothache because I couldn't afford treatment. I hurt my back and couldn't afford to go for physiotherapy.

With money, I could perhaps travel to Melbourne for treatment, or pay a private psychologist for some sessions, but I only just manage to earn enough to pay for food, basic living expenses (telephone, car registration etc) and basic psychiatric treatment.

There is a lot more to my story, but I fear I will lose your attention if I tell you any more at this stage. I would love to go before a judge or a Royal Commissioner to tell my story. It is quite shocking, not because of what I have done, but because of the awful treadmill I accidentally stumbled onto.

Thank you for your attention so far.