REQUEST NAME BE WITHHELD

A parent's experiences with the mental Health System

Background:

When our eldest daughter finished high school and gained a double degree place at an interstate university, my husband and I were thrilled. She was on her way to an artistic career and independence. At 18 years old, she was conscientious, talented and, after achieving a perfect Year 12 TER score, she'd surely be equally successful at Uni. What could go wrong?

Initially, all was well. Our daughter loved the curriculum and found part-time jobs in hospitality and aged care. She produced beautiful artwork and gained High Distinctions in both degrees. Sometimes, we were concerned by phone calls when she sounded discouraged, but we put this down to tiredness and then, a fortnight later, she'd be full of excitement about her latest project.

And then the call from interstate came. Our daughter was in the emergency department after an overdose of over-the-counter medication.

The health system lumbered belatedly into action and our daughter received a psychiatrist and case worker. The university counsellor joined in. Medication began.

She limped on. Her grades fell as her concentration disintegrated and physical exhaustion became overwhelming, but she was still (just) passing everything, and working part time. She learned CBT and many coping strategies, approaching them with the same conscientiousness she did her academic studies, while her psychiatrist experimented with various anti-depressants. Finally, she was diagnosed with Bipolar II Disorder, which is characterised by similar up-and down mood swings as Bipolar I, in which the "up" mania is characterised by psychosis. Bipolar II differs in that there are generally longer periods of severe depression, relieved by episodes of extreme instability and hypomania, with no psychosis but instead a period of elevated mood. Our daughter was "rapid cycling" – she had many episodes every year – and she had "mixed episodes", in which her mood could swing from elation to fury to suicidal depression within the space of a day or even a few hours. And these emotions were divorced from external stimuli, as if someone had numbered them randomly on dice, and periodically shook them out into her brain to see what emerged. Thus began our experiences with the Mental Health System.

Time and time again, the system has failed our daughter. When I read John Mendoza's (government's head advisor on mental health) resignation letter, our family had experienced exactly what he described when he wrote:

" Every day 330 Australians with serious mental illnesses are turned away from Emergency Departments, and 1,200 Australians are refused admission to a public or private psychiatric unit.

Every day more than 7 people die as a result of suicide, ***and more than a third of those have been discharged too early or without care from hospitals****."* (my bold)

Our experience is worth relating because one terrible episode encapsulates how our mental health system is broken, and provides signposts as to how it can be improved.

Our daughter had been back in her hometown for several months and was still highly unstable. As she got worse, she saw her psychiatrist more frequently, and he knew that she needed to be hospitalised… but there were no beds in the private psychiatric clinic until the following week, and no safe houses exist here. Nowadays, he knows her so well that he can predict the speed and severity of her descent, and book her into the psychiatric clinic before she reaches her nadir. But then, he was still working her out.

SIGNPOST 1: Establish safe houses with psychiatric and psychological care where acute mentally ill patients can be referred so they do not need to go to EDs or take up medical beds in general hospital or psychiatric wards. Such houses could be accessed via referrals from counsellors, psychiatrists and psychologists. Private psychiatric clinics and public Mental Health wards often have high level medical facilities for clients receiving ECT or other medical interventions, but many mental health patients don't need this level of medical care. Like our daughter, patients with an established medication regime may simply need somewhere secure to ride out the worst periods of their illness and indeed, a non-medical model of care may be more helpful to them.

Our daughter's Action Plan initiates when she is unwell. She sees her psychiatrist, calls emergency counsellors and family if urgent, and delivers all her meds to her local pharmacy, which she then visits daily to pick up non-lethal dosages every 24 hours. She finds this humiliating, but it's a way to stay out of hospital, without the temptation of toxic pills on the bathroom shelf. Our daughter loathes hospital, but she also knows that sometimes it is the only safe place when she loses control of her thoughts. If she feels her thoughts beginning to spiral out of control, she rings a family member to drive her into the ED. Once thoughts are out of control, it's generally too late.

Our daughter once described the nature of these episodes and the mutiny of her own mind. She's unclear because her memory is often disordered then but she says that unlike the long, ongoing periods of depression – a matter of struggling through each day and hanging on when suicide seems an escape from the pain – her acute "mixed episodes" are different. She can be well in the morning, but by the afternoon be sliding into horrific depression and mood swings – not just feelings of sadness, but overwhelming guilt and anxiety and dread, and rage and hopelessness, all mixed and muddled together. And then, she says, suicidal thoughts get thrown in, and they seem so logical. It is this cold, clinical way of thinking and, ironically, her own lack of fear that our daughter finds so terrifying in hindsight; the fact she is not in control of those thoughts, and that she cannot assess them properly. An hour later, she's terrified because of course she does not want to die, and she *knows* she does not want to die. It had made so much sense just an hour before but now she feels stupid and guilty and humiliated by what she's done.

So this day she had visited her psychiatrist in the morning. She was apprehensive because she was feeling quite bad already, and knew it would worsen in the

afternoon. No beds were available in the private psychiatric clinic for another three days. Nevertheless, we were aware of her situation, and so she returned home under strict instructions that should things deteriorate, she'd call me or her father, and go to the public hospital Emergency Department. She was desperately trying to hold on for just little longer so she could go straight into the private clinic and avoid the public system.

But things got too difficult, and so that afternoon the two of us were in the ED. Triage and a lack of beds means that we almost always have to wait hours both before and after being seen. We get plenty of strange looks, because there's nothing obviously wrong with either of us. Sometimes, our daughter briefly feels better as good numbers come up on the dice, but the muddle soon returns. And she is always confused, not so that a stranger would notice, but very obviously to us. Of course, triage nurses can't see inside her head, and so other patients with strapped wrists or hacking coughs all go first. I wonder whether John Mendoza's figures include people who turn up to EDs and are not turned away, but leave on their own accord after waiting for hours for help that seems as if it will never come?

SIGNPOST 2: If patients like our daughter with a diagnosed mental illness and with a history of self harm and control order hospitalisations or deemed at risk appear in an emergency department, then no matter how calm and well they appear they should be moved up the triage system, not relegated behind those with non life-threatening physical conditions.

Anyway, one of us is usually with our daughter and is able to persuade her to stay. Finally our daughter's name was called, and I waited outside. Half an hour passed and then she emerged, looking dreadful.

"Can you come in?" she said. "They want me to go home."

I followed her out the back and into a curtained cubicle where I met the doctor. He was practically a kid himself, but gentle and kind. I explained that my daughter knew when she needed to be in hospital and that this was part of her Action Plan as devised by her psychiatrist and herself. My daughter sat hunched, red eyed and exhausted. The fact she'd been crying in front of strangers spoke volumes.

"But I understand that your daughter saw her psychiatrist this morning, and he did not refer her then?" the doctor asked.

"Well no, because she was hanging on then," I said. "But she has mixed episodes, so things can change very quickly."

He looked at me blankly. "But she was all right this morning? She has no psychosis?"

And with a dreadful sinking sensation, I realised he had no idea what mixed episodes meant. He probably didn't know the difference between Bipolar I and Bipolar II, or mania and hypomania. And actually she *was* psychotic, but so mildly that it wouldn't be evident to a casual observer.

SIGNPOST 3: Each ED should have a *highly trained* health professional who *specialises* in mental health, so that mentally ill patients can be *properly* assessed.

"Look," he went on, "We don't have any beds available, so if she could just go home, even if it's only overnight…"

I knew there were probably no beds – another time I'd seen patients on gurneys along the corridors. But "ONLY" overnight? If only he understood! Overnight was literally a lifetime. How could I explain? "She's here because she NEEDS to be," I said. It's difficult to stay calm in these situations but shouting wouldn't help. "Please, we've been through this before, she really needs to be here." I heard myself begging and I could tell my daughter was equally humiliated, but what else could I do?

He had no idea that hospital was the last place my daughter wanted to be. She was surrounded by a supportive family and was house-sitting with her sister and a much-loved cat. At home she enjoyed cooking, gardening and many other creative pursuits, none of which were available in hospital, and where she must expose herself to strangers. Going into the ED was actually an enormously difficult thing for her to do.

SIGNPOST 4: More psychiatric beds in hospitals.

He sighed. "Ok, I'll try her psychiatrist again," he said. "I couldn't get him earlier."

Well that was a start, but I wasn't confident, and followed him half a dozen steps down the corridor to an open office while my daughter waited in the cubicle, curtains drawn. The doctor dialled. I was only a few feet away and no, the psychiatrist still wasn't in.

Just then, someone whom I later learned was part of the ACIS team strode down the corridor. He flipped back my daughter's curtain and said loudly, "I'm not going to speak to you... you were told to only come here if the situation was dire, and it isn't! You shouldn't even be here!"

SIGNPOST 5. Overworked staff with insufficient training, insufficient time to assess patients, and nowhere to put patients in need of care, are ineffective staff. They might as well not be there at all. Provide staff with backup and training. The default with mental health patients should be: if in doubt, then provide care (as opposed to, if in doubt, send them home). If this were done, by John Mendoza's account the suicide rate would immediately be cut by more than a third, or close to 1,000 lives saved each year.

Later, our daughter told us she was crushed and humiliated by these words. He was more than dismissive – she felt that he was angry that she was wasting his and everybody else's time, and I received that clear impression too. Our daughter told us he'd made her feel like an attention seeker with a manufactured illness, and guilty for asking for help.

This mental health worker had completely misjudged the severity of her illness, and the fact that she was subsequently an inpatient at a Private Clinic on a control order for over two weeks is a clear indicator that she really did need serious help, and that hospital was a necessary place for her to be. Yes, our daughter makes stupid, dangerous, inconsistent, infuriating decisions during an episode, decisions she never makes when she is well, but that does not make her an attention seeker. That's like plying someone with alcohol, and then assessing them in this state to determine their normal behaviour and motivations. Her illness causes her to make these decisions, they are not the choice of her well mind and they are a symptom of her illness.

If I hadn't witnessed that interaction firsthand, I admit I mightn't have believed my daughter had she told me. I'd suspect that her paranoia and muddled thinking had caused her to misinterpret his unmistakably aggressive, angry tone. But no. I was standing against the wall, stunned, and the next moment she rushed past me. The young doctor, who'd heard as well, looked equally horrified. "I'll try–"

I swore at him and ran outside after my daughter. Her face was rigid with a strange mix of anger, humiliation and despair. "I'm going home," she said.

She'd intended to get a taxi but I ran back in, snatched up her shopping bag of clothes, and returned. I drove her to her house and kept an eye on her. I didn't know what else to do – her state made it impossible to have any kind of rational discussion. My husband might physically have restrained her, accompanied her to the bathroom, anything and everything, but I felt it would just be a matter of time anyway, and that sooner or later she'd find something. At least all her most toxic meds were at the chemist so hopefully, she'd be all right, but infuriatingly she had anti-histamines and took a massive dose and back we went, first to a nearby private hospital because of course the ED was out of the question. But they had no emergency facilities and they sent us to another hospital nearby. Here, although they pumped her stomach, the dose was such that her heart was affected and the attending doctor told me she must be transferred to the ED immediately. By then she had no idea of anything.

"We've just come from there." I explained what had happened. He said, "I'm so sorry. The hospital system is broken, but the mental health system is completely – excuse my French – fucked." He arranged an ambulance transfer and this time my daughter was admitted, first into the ED, then into the step-down unit while they monitored her heart, and finally into a single room on the general floor, with a nonplussed burly guard at the door so she wouldn't escape or harm herself, which was laughably ironic.

Our daughter was completely confused and didn't know where she was, or what was happening. Going off all her meds for several days, combined with the physical and emotional trauma of the overdose and events, triggered a full-blown psychotic episode, which terrified her and bruised our hearts.

Much later when she was well again, our daughter wrote to the Head of the ED Department to ensure that this would never happen again, and her father and I, very angry, wrote a letter of support:

…To [our daughter's] credit she has managed to develop a range of management strategies with the help of psychologists, psychiatrists, her family, and crisis care teams to keep her safe... The last step in the list of strategies is short-term hospitalization – something she hates but recognizes as effective…

Overall her well-being has improved [but] there are still times when she needs to … implement all of her strategies to manage her illness and stay safe. Since returning [home] our daughter has had regular contact with the ACIS team… she has received crisis counseling on several occasions…

…She does not want to be a burden on the public health system but at the same time it is reasonable to expect that it will be able to respond in an effective manner in a crisis situation.

We recognize that staff are required to work long and hard (perhaps unreasonably so due to inadequate staffing levels) and that whilst most staff do their job well and should be commended we have seen first hand the dire implications of an ACIS team member who got it so wrong because he was not prepared to listen or to treat a patient with respect. This lack of consideration was apparently due to being busy and not wanting to 'waste' the time of the hospital staff and its infrastructure resources. This was rather ironic considering that our daughter subsequently spent several hours in the high dependency emergency section followed by the rest of the night in the step down unit [and] the following two days in a single room on the general floor (including the requirement for a full time security guard) and two ambulance transfers.

… The consulting ED doctor… at least spoke kindly and was careful not to exacerbate her fragile mental state. The ACIS staff member, conversely, was clearly utterly ignorant of the seriousness of our daughter's condition. That he, as a mental health worker, could speak so rudely and aggressively to a diagnosed Bipolar II patient in extreme distress and with a long history of self-harm and hospitalizations is not just unprofessional, but dangerously incompetent. Regardless of how they present, Bipolar II patients are usually not only 'sad' depressed, but also have a range of co-morbidities including various phobias, anxiety disorders, crushing guilt, self-loathing and a complete lack of self-esteem. They are not having a heart attack but are nevertheless human beings at their most vulnerable. They feel very, very bad about themselves already. No doctor would abuse a patient with a suspected heart attack for coming to the ED, but that is, in effect, what the ACIS team member did. And where else could our daughter have gone for emergency mental health care? [Her psychiatrist had] that very morning advised her to go to the Hospital ED should her situation become dire.

…We are … very frustrated that the situation could have been so easily avoided.

…We support our daughter's request for the following from the Hospital:

- *That the Hospital recognize that our daughter's case was initially handled very badly (in fact dangerously) and that this be brought to the attention of staff, especially ACIS staff.*

- *A letter of apology from Hospital to our daughter acknowledging that her initial presentation could have been handled better and should have been treated with greater respect and empathy. (We do not expect or seek Hospital to accept any responsibility for our daughter's decision to overdose).*
- *That ACIS staff are made aware of the specific symptoms and risks associated with Bipolar II Disorder.*
- *Confirmation from the Hospital that staff have actually been debriefed and an outline provided of what measures it has taken to ensure such a situation will not reoccur for our daughter or anyone else.*

We also urge your timely attention and response to the above issues. Our daughter is not stabilised and, understandably, is now highly fearful of attending the Hospital ED even in the most dire situation when she is at extreme risk. A reassurance that our daughter will not be treated in the same way, and that her Bipolar II condition is acknowledged as serious and requiring acute care, may literally be the difference between life and death for her.

The hospital administration agreed to meet with us, but our daughter was so traumatised by her experience that it was months before she could bring herself to come in – even driving past the hospital was enormously distressing. To her credit, the (newly appointed) Head of ED bent over backwards to provide somewhere our daughter would be comfortable but even so, we could see that it took all her courage not to bolt. The Head apologised unreservedly. She understood the aim was to ensure that our daughter would never again feel unable to come to the ED for help, and she was supportive, gracious and genuine in effecting this.

We also received written confirmation that changes had been made and hopefully this was true, for the sake of other mentally ill patients. For our daughter, it was a positive outcome. At a subsequent visit our daughter was at least admitted more quickly and without a fuss (we didn't need to beg), and whether this was due to a change in procedure, a quiet day or a big red warning sticker on her folder, the result was much less traumatic for everyone involved!

Of course, many mentally ill patients are in no position to complain about their treatment – indeed, they may not even be believed.

I have written this to convey that mentally ill patients are human beings with families and loved ones, not second class citizens. That even when mentally ill patients act irrationally, in a way that is infuriating or frustrating or annoying even to their families, let alone health professionals, that this is often outside their control, and that they still require complete respect, and to be listened to. That families are often a vastly underutilised resource and that consultation with and respect for families, partners and clients make a real difference to outcomes.

As I write this, Julia Gillard and Tony Abbott are leading up to the election. To my amazement, Professor McGorry, John Mendoza, organisations such as GetUp! and other mental health advocacy groups have had some success in making Mental Health an election issue. Funding has been promised by all parties and of course nothing can happen without money. But I suspect that politicians who have no direct experience at the pointy end of public mental health assume, as we once did, that

yes, a few people might slip through the cracks, but that most mental health clients are well served. Our experiences – and we have private health cover to help! – tell us that the reverse is true, and I would not have believed that a first world country like Australia could be such a dysfunctional mess. Our family is in the strongest possible position, so the system would be unimaginably worse for those who are inarticulate, illiterate, unassertive, unconfident, irrational, emotionally damaged, alone or without family or friends to advocate for them.

Our daughter has now been stable for almost a year. She sees her psychiatrist regularly and is on a complex medication regime but has needed no counselling, crisis care or hospital admissions. She works in disability support and counselling and is about to increase her hours a little and suspend her DSP to see whether she can maintain good health… and this wonderful, productive, creative, caring human being was nevertheless almost lost to us all. Such a waste, and yet this waste is playing out all around Australia every day.