

My Story

My son is now 33 years old. He was diagnosed with the onset of schizophrenia in his early 20's. He has never accepted this diagnosis. He is not fully aware of his condition and is resistant to taking his medication. When my son is well, he is a functioning individual.

In the early days of his illness he was treated through the "Head-Space" program and this led to good results. But after the age of 25 he could no longer access this program and his condition deteriorated. The current system, which results in hospitalisation followed by release on a community treatment order, to then be discharged from the system with no further follow up, is set up to fail, particularly for people with my son's condition, who are often resistant to treatment. The ripple effects of this are huge. For every person with a serious mental health condition the effects on carers, employers, family members and members of the community are immense. The economic burden of this in terms of loss of productivity and work hours must be compared to the cost of effective treatment.

There is a big problem for carers in the way patients' human rights are prioritised in the system. How can someone who has a profound mental illness make safe decisions about taking their medications or whether they need to be hospitalised? Medical Tribunals bend over backwards to cater to patients' opinions on these issues but not carers' opinions. Carers are put second to the opinions and wishes of patients whereas it is often the carers who have a much clearer idea of what the patient's condition is and what the patient actually needs in terms of treatment. I can accept that we respect the patients' human rights, but does this mean that we let that person self-destruct?

CATs: In terms of the health care system it is my experience that you very rarely will get a health care professional in the CAT system who displays any empathy for either the patient or the carer. They give the strong impression that they are just "doing the job". You also never know when the CAT team is coming or how long it will take for them to arrive when your loved-one has a serious incident. The process is highly intimidating to the patient. You have three people arriving and they are in your home. Often, it's a different three-person team at every incident and they work through a long question checklist which we have all been through numerous times before.

I would strongly recommend that the Royal Commission considers the following measures to help improve the system.

- 1. One thing that was highly effective and helpful for my son was the Family Liaison Officer.** Not every area has these, but we were lucky enough to be in one that did. Every area should have at least one dedicated liaison officer who can assist the patient and the family to access the system and navigate their way through it. The officer can also help advocate for the patient with health providers and help "translate" what the provider is saying to the patient and vice versa.
- 2. There needs to be better and more effective training for mental health care providers on how to treat patients with acute conditions such as schizophrenia.** Over and over my son and I have found that many providers don't have specific knowledge about the symptoms and consequences of really acute mental conditions and tend to lump them all together. Better training, especially among providers who might have first contact with patients is essential.
- 3. Youth facilities but also adult facilities for people suffering from acute mental illness are dismal, drab, and depressing.** Couldn't something be done to make them more cheerful and welcoming looking? I think the drab nature of these facilities has the effect of exacerbating the patient's condition in many cases and makes them not want to go there.
- 4. The opinions, experience, knowledge, and commitment of carers should be properly utilised.** Carer's bear the brunt of looking after and even treating patients and their knowledge of their loved-one's condition is probably better than anybody else. Providers should take this strongly into account rather than ignoring or dismissing it. It is really the system that needs to be changed here—a better cultural understanding of how carers enhance the process.