Submission to the Royal Commission into Victoria's Mental Health System

Supporting Document

I am a caring mother who cannot believe what I have seen in dealing with the mental health system.

When my son was 17, he developed a mental illness. Before that he was wonderful at school and had lots of friends.

When he had his first episode, he was taken to ______, which is part of ______. I was trusting and they didn't seem too badly. I had no experience in mental health, and didn't know anyone with a mental health problem.

He was released from there, and I was told that if he took the medication he would be ok, even if he took drugs. I have now learned that it could be fatal. I tried to wean him off the drugs, but he did experiment with drugs.

When he was 21, he was in hospital, he was given an injection. He didn't want to have the injection, and while it was never discussed with me, they still gave it to him. When he came out, he was in a worse situation than when he went in. One of the biggest challenges was that I didn't know what was happening.

He had terrible side-effects as a result of the injection. He was still hearing things. They suggested giving him another injection, after I had read a little about it, and the bad side effects associated with it. The hospital coerced him into having it. He was injected, despite concerns from the nurse that he had a high heart rate. It was shocking that they pushed through and gave it to him, and I was screaming at them. After they gave it to him, he was a shell. He was absolutely frazzled. They just gave him this particular drug without checking out all the circumstances.

At this point he was on a community treatment order. I informed the hospital that it didn't work. After the second injection, I had someone profoundly unwell. They recommended more pills, and this made him even worse.

I said to them if they give him another injection, they had to do it under their roof. After they did that, they discovered that it didn't work, which was what I had been telling them for two months. We ended up discussing the situation, and I told them that if he stopped taking drugs and medication, he would be ok. They let that happen, that he could go to the unit with a trial of no medication.

Within the first two days, he was still quite unwell. But after two days, the real person was back, and he did really well for the rest of the week. All the nurses were saying "we've never seen him so well". I said it's because "he's not on medication", and the hospital responded poorly, and lied to me about the whole issue. They just determined to drug him.

After that week where we had a meeting with the hospital, where I was pleased with how he was going. The doctors said "he's still hearing voices" and the doctors refused to say when, stating that I would need to go to Freedom of Information. I then asked for an interjection to have a tribunal hearing. This took another three weeks, and within the month off the medication, (except sleeping tablets which I opposed). He was great in the hearing, and they said he could be treated in the community, without medication.

A few months later, he began smoking marijuana again, but he wasn't too bad. A few months later, he had a meeting with the psychiatrist. That morning he had smoked marijuana. He was in a good mood and happy to see the psychiatrist, but she said that the way he was behaving, he should be on medication. I said to her that the long term effects are very bad, and her eyes glazed over as though she didn't care.

We managed to get him to stop smoking, and he was doing well. Despite that, the hospital called, stating that he needs to be medicated, and that I would have to bring him. I said he won't be medicated until he has had a further consultation. The next thing I know, the police are at my house. I explained the system to them and they were understanding, given the reputation of the hospital.

In the meantime, we informed my son of what was happening, and thinking he was about to be medicated, he went to the city to have a big weekend. And, by the time he returned, he was mentally ill. At the end, I got him to the hospital, because he's had a panic attack from the threats from the hospital, took drugs to forget about it, and then was once again in a worse condition.

We went to hospital and he was very unwell. That night he escaped from the hospital. He walked an hour and a half home, and I had to go through the whole thing to get the police to come and get him. By the time he got him, he was more unwell.

The next day he was medicated again, including medication I had asked for him not to be taken. We went to a second tribunal, he had a powerful lawyer, and we got off the community treatment order. Because I fought it again, I was just left alone with him. Went well for a while, tried a number of alternative treatments, and found new ways to deal with stress through meditation. After a while, it was difficult to get him there. He didn't think he had a problem.

I put up with him four around six months, and at this point he decided he won the lotto. He got a scratchy, and thought he had won millions. He claimed that I stole it and was trying to prevent him accessing it. This led to him being admitted again. While he was in hospital at that time, he was so over drugged. I received a call that he had a fall, and that I should come and get him. They wanted me to take him to outpatients in the morning. It took days for him to receive medical treatment for a wound that took 15 stitches, even though he was already in a hospital.

In the meantime, I had sold my house. When he was released, I was moving house. I moved in with my partner, and my son became aggressive toward my partner. They put him on another injection, which resulted in him being more unwell and aggressive. He would tell me I was a liar, that I could hear the voices too. He was housed in an assisting living facility. The treatment in the facility he was in was very poor, and they seemed unwilling to help him, and accuse him of being badly behaved, not unwell.

After that, he was admitted again after becoming unwell, and became distressed that he would become homeless after being discharged.

They refused to give a gene test despite requests, and continued to medicate him. I contacted the complaints person of hospital, and said that I need to get the test done, rather than continuing with the injections. They finally ended up doing the test. But when we had a meeting with the hospital they didn't know whether he had the test done, and suggested I do it (which I had been offering for some time). I was told that the hospital would continue medicating him. I responded that I was concerned that the drugs could end his life, and the woman from the hospital said, to paraphrase "what does it matter if he does die, what kind of life he is living now?"

After that, they gave him the medication, he became upset, and so they injected him with more medications. I looked up the second medication, and it was stated that the two medications should only be used in **extreme caution.** The hospital were adamant that had to give him this dangerous cocktail of drugs.

I complained to the mental health commissioner. The response was poor, and different address our issues. I understand that they are still working on other complaints we've made.

Once we got the gene test done, which the doctor didn't know. It told us that the drugs he was being given had adverse impacts. All the drugs were either dangerous or ineffective, according to the gene test. They caused so much pain, hardship and distress for my son and my family, despite the information being potentially available that all of this could have been avoided.

Despite that test, they still wanted to give him the dangerous injections. I had to fight again to try and ensure he got medication that actually worked.

After having screamed and yelled a lot, he's finally on the medication. They then placed him in a dangerous facility. I had to buy a house so my son could come back and live and with me. I thought I would be able to get away from _____, and couldn't get into _____.

Now, he's in the adult facility, and it feels as though there's a lack of information about his case history. It's concerning that now he's in the adult system, it's distressing to have to start again.

One of the other challenges is that unless people are willing and able. One of the requirements at ben a short stay place such as _____, is that patients need to have a severe mental illness. But they are also meant to have goals, and to know what they want. Even for those without a mental illness may not have these goals.

I am also disturbed by staff in medical facilities, sitting behind the glass, not assisting patients make it more distressing that people aren't getting the treatment they need.

At one point, twenty days after being seen by a mental health community treatment team, I was told I would have to take him to hospital immediately for medicating. Having not seen him for nearly three weeks, his condition had changed. They didn't ask about how his drug use may have altered things, or any changes.

The general culture of the hospital has been one of a determination to medicate my son. Not only has it made things worse, and made my son more unwell, but as a system, we cannot simply rely on drugs to fix the mental health issues our community faces.

Where the system has failed you:

- Over medication. This has been the only approach. Some of the drugs were dangerous, others
 infective, and many had terrible side effects. Some could have even killed him. They didn't make him
 better, or help us manage him, they made his brain worse.
- **Information and communication with carers.** We constantly felt as though we didn't have enough information or were excluded. Or were given treatments that we disagreed with.
- **Safety.** He was so over drugged that he fell and hit the corner of a table and cut his face. He didn't know what had happened.
- The treatment we had received from has been distressing and made my son's condition worse. At times they have felt indifferent, or determined to provide drugs, despite the evidence that wasn't working and making things worse.

• I am concerned that there is bullying in the workplace.

Positives:

• They listen, they have worked with us and it's been completely different to the other health professionals.

Recommendation:

- Put in **mystery workers and patients** in order to review and report on the system. Too many times I have been lied to about treatment.
- There needs to be more inclusion from the family. We need to be able to share information and work with the medical staff, but all too often we are made to feel as though we are part of the problem.
- The hospitals need to recognise that everyone's different and need different types of treatment.
- We also be thinking about who we put together in mental health facilities. Often it makes tough situations worse.