

# 2019 Submission - Royal Commission into Victoria's Mental Health System

SUB: 0002.0009.0058

## Name

Anonymous

### **What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?**

I have outlined suggestions in my brief submission. These included a campaign as part of a national event highlighting mental illness. Community forums and activities to increase mental illness awareness.

### **What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?**

"Providing better diagnosis tools would be beneficial. At the moment, most of the diagnosis seems to be subjective. From my experience, thorough objective assessment via questionnaire is only used as a last resort. In the case of mental health practitioners treating patients who are already in the care of a doctor or case worker, there should be more collaboration between them to clarify diagnosis and treatment."

### **What is already working well and what can be done better to prevent suicide?**

██████ is a vital service that could use improvement. Staff need more time to address issues. I have heard on more than one occasion of callers being asked to wrap things up before they are ready to cease their phonecall. This is a dangerous way to deal with desperate people who are at times on the verge of doing drastic things.

### **What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.**

"Rising cost of living exceeding rates of pay. Lack of well-being programs in the workforce and in schools. Expectations that workers in many fields work overtime, sometimes without pay. Poor work/play/family balance. Lack of awareness on the issue of mental health. A need for our communities to learn about meditation, relaxation and the importance of sports and social outlets."  
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### **What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?**

N/A

### **What are the needs of family members and carers and what can be done better to support them?**

"Family members need to be heard. Confidentiality and privacy laws can be a barrier to doctors communicating with freely with family and involving them in important decisions regarding care for their loved ones. Family members need to be considered somewhat of an authority on their loved

ones' health, temperament and moods. This could help inform treatment and diagnosis. "

**What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

N/A

**What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?**

Services: -upon leaving acute care to bridge the gap between hospital and a normal life. -to improve patients' chances of returning to the wider community. -which are not only aimed towards the most severe and long-term mental health sufferers. - that cater to every stage of illness and recovery.

**Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

'-MEDICATION: Availability of medications and ease of obtaining them with regard to their addictive nature and potentially devastating side-effects. Lack of product information given by doctors and nurses administering medications. -DIAGNOSIS: I would suggest two doctors be present whenever medication is administered to a patient for the first time. This would allow a better before and after comparison to be made to assess for patient's improvement on medication. Less subjective diagnostic tools to be used when assessing and reviewing patients.

**What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

"Education and training for the current mental health workforce, outlining opportunities for improvement and explaining what steps have already been identified to resolve issues. "

**Is there anything else you would like to share with the Royal Commission?**

"I would like to attach an account of my experience with mental health services that occurred in 1997 until about 2000. However, my most recent experience was in 2014 when I developed perinatal anxiety and found the response from my own GP and people in the hospital system to be severely lacking. One nurse told me that I shouldn't act like a ""teenage mother"" , although I was in my thirties and experiencing a fairly common pregnancy condition - she obviously had no expertise in perinatal mental health. My own GP said I wasn't depressed, but then his colleagues declared that I was. The psychologist he referred me to said it wasn't her role to be nonjudgmental. It was a really stressful time for me, and there was very little agreement between the medical staff about my condition from one person to the next. It was similar to my first encounter with mental health services which I feel is the more concerning of the two incidents and the account of which I'll attach in a separate document. "

I recently attended a Royal Commission session in Dandenong to give my feedback on the Victorian mental health system. I briefly explained my history beginning in 1997, hoping it would highlight opportunities for improvement in areas **including accountability, attitudes in medicating and accuracy of diagnosis**. However, time was limited, and I came away feeling as though I had been doubted or misunderstood. There were some mental health workers present and I had forgotten what it was like to experience the indignity of being labelled whilst seeking help for inappropriate treatment and misdiagnosis – to explain your situation only to have it turned into a set of symptoms so that finding resolution is like banging your head against a brick wall.

Telling my story publicly alongside others who were sharing for the first time, was initially a cathartic experience. However, a mother who had lost her son to suicide or parents who continue to have their daughter turned away from high-care treatment may not have understood what I was doing in the room. Theirs are vitally crucial matters requiring immediate attention; however, I feel that my experience is another symptom, albeit in a different way, of a system that needs review. I fell through the cracks when I was able to easily access drugs that should not have been given to me and I was unable to leave the system until I insisted on a thorough psychiatric review and was discharged, initially against the advice of my treating psychiatrist.

I've outlined my experience below and highlighted in bold issues I have identified and suggestions for improvement:

- I began to experience mild OCD symptoms at 14 years of age.
- At 17, I asked to see a psychiatrist and was referred reluctantly by my GP.
- The psychiatrist said he was unwilling to prescribe medication for my generalized anxiety, but that he would talk with me about life issues. I left school and spent a year in sessions without moving forward.
- I visited the ER for a second opinion. **The doctor gave me valium and left all responsibility for taking it in my hands. I was not informed that it was the same "valium they take on the street"** as one nurse put it during my subsequent home visits. **Perhaps having another practitioner in the room may have deterred the doctor from taking such a blasé approach with me. Full disclosure of all the side-effects, paradoxical reactions and safety of the drug could have been given before administering it.** I proceeded to become very unwell and returned to the ER where a nurse diagnosed a "panic disorder".
- My own psychiatrist referred me to the CATTeam who began to visit my home, adding other drugs to the "treatment" schedule. **The first anti-psychotic I ever took was given to me by a nurse.** After some disagreement amongst the medical team, I was then referred to another private psychiatrist (I think by my own psychiatrist) who diagnosed a schizophreniform disorder.
- When I returned home, my CATTeam doctor was shocked to learn I'd taken stelazine. He had been weaning me off all medications. When the CATTeam finally ceased all visits, I was down to a dose of a newer antipsychotic so small it was "barely working" according to the nurses.
- It was during this time that I asked my own psychiatrist if he had known the medications were making me ill and he replied, "Of course I did!". He later handed me a "Release of information" form to sign and under it was a "Release from liability" form. The CATTeam wouldn't give him access to my files and he needed my signature to view them, but he was also apparently concerned that I might sue him.

- A few years ago, when I ran into my former case manager from the Outpatient clinic he admitted that, “he didn’t think there was anything wrong with me at that time”. In fact, he had negotiated on my behalf with the clinic doctors who had initially said it would be necessary for me to take anti-psychotics for several years. **By completing a thorough psychiatric assessment via a questionnaire**, they determined that I would not need medication and so I left their clinic and ceased all medications.
- It was incredibly hard for me to transition back into a normal life. **I had been entrenched in psychiatric services but being a relatively well person stuck in the mental health system was doing more harm than good. There were no services catering to people with psychological conditions to support return to work and study.**
- **I had been threatened with treatment by injection and involuntary hospitalization; misdiagnosed and instructed to never do anything stressful. I was told that “meditation and relaxation techniques” would not work for me now - that it would always have to be drugs. My sanity had been called into question, my self-esteem undermined – my family feared I would be stuck in the system forever.**
- **The biggest indignity and obstacle for me was the inability or unwillingness of medical professionals to hear what I was saying and believe me.** They had determined that my main psychotic symptom was circumstantial thinking, i.e. my “idea” that the medication had caused my mental health to deteriorate. They had decided that questioning or “checking” my treatment was my obsessive symptom (but they had yet to diagnose my family in the same way!) I can see how under their reasoning they would label me as such; however, I was not clinically ill to begin with. I was under the impression it would be ok to see if medications would work for me with little knowledge of the consequences. The initial “treatment” snowballed into a complete disaster where one decision and diagnosis influenced the next. My family will also attest to this.
- **The CATTeam and private psychiatrist hadn’t seen how I’d presented before taking medication and this was a big problem.** When they asked me why I was taking medication, they literally could not believe my answer – as they said, “who would take such unsafe medication just to see if it worked?”
- In 2009, I foolishly went back to the ER for a review of my past treatment and came up against the same thinking that had seen me misdiagnosed. The ER nurse sent my GP a letter of outreach who, upon reading it, shook her head and said, “If you present to these people in an emotional way - upset and crying – they are going to diagnose you with something.” Her advice was not to return there again.
- I have since moved forward with some measure of success, although I was diagnosed by my GP with PTSD. Initially I lacked confidence in all aspects of my life. However, my achievements until this time have included:

\*obtaining a diploma;

\*working as a manager for many years, overseeing various departments, in a busy, public-facing role;

\*maintaining a long-term relationship and starting a family;

\*being off medication since that time and being “symptom-free” except for my original anxiety, PTSD and perinatal anxiety in 2014.

In conclusion, I have not had any psychotic symptoms as predicted by the treating practitioners. I believe this shows that **the proposed treatment for several years would have been unnecessary and may have caused some damage in the form of lingering side-effects, mental deterioration, possible mental illness, further damage to my sense of self-worth, negative impact on future relationships and other endeavors, possibly both educational and work-related.** I did not have a “return” of any symptoms with which I was diagnosed.

I have in fact had medical professionals corroborate my story. But **I understand it is difficult for people in this field to be very outspoken in their support of misdiagnosis and this is an obstacle to healthy people getting the help they need in the face of what can be a very subjective process of diagnosis.** I wish the team of medical professionals had **listened closely to what my family was saying to gain more insight into what was happening.** If they had listened openly and without judgement, I may have been able to minimize the effects of this traumatizing experience.

I have withheld all names and identifying details in this account, but I would be happy to discuss my experience further at a future date, should you wish to contact me. I welcome change to the current mental health system in the form of a positive cultural shift to a place where such an experience can never happen again.