

Although I first received treatment in 1999 I understand there have been many changes made since 2014, so I feel it's important to remain focused on what has happened in my story since.

I feel it's also important to acknowledge that a great many of my friends are suffering or have suffered too. Some are going through much harder times than I and won't have the opportunity to speak up. Others did not find out about this in time as the information was not made obvious to the public and was very difficult to find. For others it is too late.

All I can do is keep to my own story, as that is all I know.

By 2017, I had been employed at a major retailer for 10 years, originally getting the job through an unpaid training program due to my diagnosis and the fact I was on disability support. The training provider Training Works told me I would only get the job if they removed my illness, Schizophrenia, from the application form. Though I told them I was not happy with this, they did it anyway.

After working with a number of different managers over the course of the decade, there was one who didn't like me. Not recognising her bullying behaviour for what it was, I instead pushed myself harder.

Seeking help from doctors seemed futile. I was questioned every time I saw a doctor by the manager. None were willing to change the medications I was on though they made me drowsy and did not help. Internalising the blame, I became both mentally and physically sick. Despite the advice I sought regarding the medications, my questions remained unanswered. I stopped taking my medications after much debate and research of my own which led me to what I still feel to be a rational decision.

I stopped abruptly however rather than scaling the dosage down gradually. I was unable to sleep and down to 35kgs or less. When I had my period the agony was so intense I thought I had a miscarriage. Though I was traumatised physically and mentally by thinking I had killed someone when I felt the loose skin around my stomach, I went to work the next day. When the agony became unbearable that night as I lay bleeding and convulsing on the bathroom floor unable to reach the phone, I had to go a doctor the following day despite it being against the expressed wishes of the manager. As there wasn't one open nearby that would bulk bill at short notice on a Sunday, I called my Mum and asked her to drive me. Upon finding out I hadn't been pregnant, I was relieved but knew I had to try harder to get better, thinking it was still my fault.

My cycle stopped completely after that, and I am still waiting for to return so I can find out if I will be able to have children or not. After every test possible, the last gynaecologist I have seen thinks I am doing well, but I am still waiting to see.

After this, I tried even harder to get better. I was seeing doctors on almost every day I wasn't rostered at work. Forced to skip breaks, I didn't have time to catch up on

eating or sleep, although I was trying. I started at the G.P. but went on to see a psychotherapist at works request, despite the cost of \$100 that I paid each week for about 5 weeks. The GP I was seeing kept changing though I was going to the same local clinic. The first had recognised that I was in a severely damaged mental state by that stage, while by the time I saw the second the reasons for my ill health were becoming more clear. I requested an appointment with a nutritionist. It was never booked as after a week of having a food diary the GP could see that I would eat healthily if given time, space and permission to take care of myself.

But I was not. When I requested a 3 hour per fortnight reduction in shifts to allow me to cope with the increased doctors appointments, I was told I needed to have a letter written by the major retailer's HR department signed by the psychotherapist. When I asked if it could be signed by the GP I was told no., it had to be the same psychotherapist. When I took it to the psychotherapist she could not understand how to make sense of it, instead calling the manager directly with my permission. The manager then told me the roster would be adjusted, yet the changes were never applied until after I left, affecting only my long service leave.

Isolated and suffering from extremely low self-esteem, I felt I was a monster and a burden upon the world. At work I was told I simply unwilling to learn and by the new year I was suicidal.

Still my condition worsened as I continued to push myself harder just to better. In February 2018 my cat became ill due to my stress. Awaking to blood in his urine and vomit on the floor, I contacted my Dad for help in making a vet appointment while I went to work, letting them know I would be half an hour late as I had missed the train. Out of all the doctors and other professionals I had seen so far, I found the vet's advice the most helpful. My cat has since recovered, much to my relief.

I was only able to continue working for a few days after that, barely making it through the extreme bullying of Monday 12th February 2018. I saw the GP that evening and was due to see the psychotherapist the next day. A friend who had been very unwell herself at the time contacted me to go to a charity event and I was desperate by that point to have some social contact. I had rarely seen friends or family throughout this time and was realising how severely isolated I had become. Originally planning to fit in both, I instead contacted the psychotherapist requesting the appointment be changed, or done via phone.

Having not yet heard from the psychotherapist, I travelled from Boronia to the city to see my friend. While trying to relax and explain the situation to her, I received a call informing me that I was to wait for the C.A.T.T. (Crisis Assessment and Treatment Team) to contact me. I attempted to explain that my phone was very low on battery. I was told to simply go and charge it, despite it being an older phone and having a different charger to many more modern ones. Another friend lived nearby and I was able to charge it there, but I did not want them to be called. I was terrified of being taken to hospital, of losing my pets, my home, everything. When they called

me and demanded I be at home by the next morning, I just needed to know what time. I knew I hadn't eaten or slept and I needed to know what time to open the door. They refused to tell me, instead lying and telling me a time I later found to be before they start making house calls. They asked me if I had anything that could be used as a weapon, such as knives in the house. Furious by that point to be so patronised, I told them I have a potato knife. They then proceeded to tell me in a very rude tone that if I had a problem I could go to the nearest hospital. When I began to tell them I didn't know where that was, I was hung up on.

In shock that this could happen, the two friends I was with travelled back to my house with me to ensure I stayed alive. Once we were there, I cried until I vomited, and passed out next to the toilet. I was then moved to the couch by my friends where I slept until the middle of the night. The others were still awake so I made us all dinner, then it was their turn to rest while I prepared myself for the C.A.T.T.

When they arrived, I finally had food in my stomach. I felt safe with friends nearby and was relieved to be away from the stress of work. For the first time in a long time, I felt happy. I was willing to work with the C.A.T.T. allowing them to come inside and answering every question they had, though most revolved around which drugs I had or had not taken. Although I did not appreciate my situation being confused with an addiction or drug-induced psychosis I kept answering.

They came to my house every day for months following that. Due to this I was unable to adjust to a routine, as I was never told what time of day they would arrive. I was unable to leave the house to buy groceries, as they would call me and tell me to come home if I was at the shops. It was different people every time they came, so I was unable to build a trusting relationship with any of them. They quickly ensured I was put back on medication. Though it had a different name and different side effects, the C.A.T.T. (including the doctor they sent) were unable to tell me how the positive impacts, if any, differed to the Abilify and Mirtazapine I had been on.

By then on Valproate, Olanzapine and Valium, I told them I was happy to take something if it helped, but did not want anything like the one's I had been on, which had a great number of side effects beyond drowsiness. They assured me, without giving me access to information, that it would be fine, to not worry about it. At one stage when I was given information it was 'by mistake' and taken away from me. My concerns regarding serious side effects were disregarded, as was my work situation.

Losing money quickly as I was still supporting myself off my savings alone, I had no income while on unpaid sick leave. This only caused further distress, yet the C.A.T.T. were unwilling to listen to my concerns. They repeatedly told me not to quit my job, refusing to understand where the original stress had stemmed from. I was not provided with any information or help in dealing with WorkSafe, despite asking many times. I was desperate to change the medications as they were having further negative impacts on my health, along with wanting to see a dentist due to the damage the stress had done to my teeth, which I could feel were becoming loose.

I was given blood tests, yet was never told the results, particularly the nutritional information I had requested. Instead I found out 9 months later through the GP that I was low in B12 and supposed to be taking supplements.

When I called the after hours C.A.T.T number, I was either told I had called the wrong number, or sent to hospital against my wishes.

Having called to ask for more information on the Valium I had been given, the police and ambulance were both called. They arrived at my house, standing with the door open though I repeatedly requested they close it due to my cat. He was terrified by the situation. I had only time to get my toothbrush, though they kept assuring me I wouldn't have to stay and would be home again that night. I still did not understand why I had to go at all. I was also concerned about the ambulance cost, though told it would be free I had never heard that information before and did not trust it. Once at the hospital I was left in emergency overnight. Without having seen a doctor or other medical professional and cramped from trying to rest on the waiting room floor, I only wanted to be home with my cat. I eventually asked reception where I was, as I did not know what hospital I had been taken to. I was simply told that I was in hospital. When I asked the address or nearest train station, the receptionist did not know. It was another patient who kindly directed me to the bus stop just outside, so I thanked her and left. I had been there over 8 hours.

Calling Lifeline ever since, they have been a great help to me, although there are often times when I can't get through.

During this time I was consistently told by the C.A.T.T. that I had to wait to go to an appointment that had been booked for me before the medications would even be discussed. Yet that appointment was repeatedly cancelled, often without my knowledge. I kept asking if I could see someone else in the meantime and was told that was impossible.

Meanwhile the visits were reduced, before being cut off completely. With the Olanzapine causing me to become sicker, I additionally had the flu for a month, during which time I was unable to get off the couch and get water, but the C.A.T.T. had gone by then. Running out of savings fast and still requiring expensive dental treatment, I had applied already to centrelink for sickness benefits but my claim was never processed. Finally I went to WorkSafe, but was not well enough yet to cope with the added stress this entailed. The GP's reports were ignored, despite him showing me what he had sent I was told it was never received. With no chance to explain what had happened, I was instead questioned on my high school life, despite the lack of relevance. When I began to mention what had happened at work, I was told there was no time left. My claim was refused on the grounds of a 'pre-existing condition' and when I asked if that meant the boss could do whatever she liked to me, I was told yes.

The statement was sent through to me and once I had seen the extent of the lies it contained, I gave up. Emailing both payroll and the store to ensure the message was received, I quit my job. I never received a final payslip or separation certificate. When I went to centrelink again, my newstart payment was withheld for months as they refused to believe that I had not received these, calling me a liar instead.

Spending a month on the couch depressed, my medications were changed repeatedly, each one with more negative side effects causing me to have to change back to the Olanzapine each time. At times I was unable to get in touch with a doctor and would have to make the best decision I could on my own.

By the time my centrelink payments were processed I had another job. Provided with the same paid training as every other team member this time, I went from casual to part time within a couple of months.

Currently I am still working 15 hours a week, along with undertaking the certificate iv in Mental Health full time. I am also planning to go on and complete the lived experience qualification. If the certificate iv had not been made free along with the lived experience units being made affordable, I would not have been able to do this. A further improvement would be to include the lived experience certificate under the free TAFE scheme next year in order for more people to access it. At the same time I am volunteering once a week. I am still able to maintain the rental I am living in while regaining my health, without relying on the help of others. I still attend appointments with a case manager and doctors and after many medication changes I have found one I am able to function on physically. Panic attacks, psychotic symptoms (such as sensory hallucinations) and sleep symptoms can still cause problems for me, yet I have been able to develop my own methods of reducing their severity.

Although I feel my recovery was made much slower by the C.A.T.T. I was able to gradually help myself to get better. I believe this demonstrates that if permitted the freedom of risk to make our own choices, such as leaving work when it is necessary to move on, it is possible for people living with a mental illness to achieve great things in our lives. Most people don't choose to have an illness, be it physical or mental, yet our experience can be learned from and utilised to benefit those who are suffering when they need it rather than persistently telling us we are wrong for questioning our treatment.

It is only through these questions and from seeking the answers from those with the experience to know that we will be able to progress forward in science and society.

I don't want pity, sympathy or patronising. I just want to be recognised as having the same rights as any other person, with the freedom to share my experience. Yesterday, 3/4/19, someone from class told me my lived experience in particular was as important in that class as the teachers. I've come a long way and I don't plan to go backwards now, but please don't make it so hard on others. We don't need to be punished when we are unwell.

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

Organisation Name

N/A

Name

Miss Trinity Ryan

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

"Better education for the public, beginning with those who suffer, then family, carers and any others who are close to those living with a mental illness. This needs education also needs to start earlier in schools, as children are able to understand much more than we give them credit for and can often cope better if given tools to help them learn and are aware of when to seek help. Speaking from my personal experience, I believe more knowledge and preparation could have drastically impacted upon my own self-stigmatization, which led me to avoid help for many years as I was suffering from psychosis in high-school. When I finally did receive help, my parents would have been the best ones to assist and facilitate this as I had been very close with both of them. However, they were not given the information they required to take care of me, even when I was on suicide watch and though wanted desperately to help, were unable to do so. By allowing the community better access to the best and most relevant information through all levels of education, including through social and more traditional forms of media, we empower our society and ourselves as individuals to take control, working towards a holistic recovery based model. More powerful laws concerning workplace stigma and bullying. It is never right to be told I can be treated "however (the boss) wants to" no matter what pre-existing condition I may have. Bullying is still bullying."

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?

N/A

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

"Life line works well, due to the way they will have a genuine and understanding conversation with people who are going through difficult times without hospitalization unless necessary. From my own experience, when I feel suicidal, the last thing I would do is call the Crisis Assessment and Treatment Team or 000. Knowing that as soon as the word suicide is mentioned I will be taken from my home against my will by the police, ambulance, or both, only to be locked up in a hospital would keep me from making that call. My past experience only reinforces this, as I was taken to emergency and left there alone overnight without seeing a doctor. When reception was unable to tell me where I was or the nearest train station, I relied on the one remaining patient who kindly directed me to the bus stop outside, where I waited for 40 minutes in the cold before finally starting my long journey home. We need facilities that aren't hospitals, a step-up, step-down facility where people are able to stay for short times until they are well. I have been told by a nurse when I was 18 and suicidal enough to require ECT that "hospital's not a holiday, you know" however there are times when a person's mental illness becomes so overwhelming that they are unable to cope with the things they would usually do. At times like these, sometimes people do just need a bit of

a break. It's not a holiday, but rather time required to heal."

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.

"Continuity of care, along with choice. People need to have the right to say when medications are not working for them. With such hugely damaging side effects, including death, we really need to listen to the opinions of those taking them as to whether or not they work. It is no good science telling us it should work if it doesn't, or if it only does for some. While I understand that these medications need time to work, doctors also need to take the time to sit with their patients and listen to them. It is often much easier to build a rapport with a doctor or other health worker if clients have the choice of seeing them again, so we require that option rather than being constantly told we have to move on. We also require the option of seeking second, third, or as many opinions as it takes to get the help we need. Currently, the vast majority of G.P's will not alter psychiatric medications and as a result clients are forced to either pay specialist fees (costing approximately \$300 per half hour) or wait until they are at crisis point already before receiving emergency psychiatric assistance. It is also a very disjointed system, with nobody seeming to know the full range of services available. Many people are unable to get an NDIS package at all, but even for those who have it does not cover the expenses they require towards improving their health."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Access to housing may improve outcomes for many. A base level income for all would additionally help as it would assist to combat the problems associated with low levels of income without stigmatizing anyone.

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

"Education. While confidentiality remains essential, family members and carers need the best information they can access in order to help those they care for. People living with mental illness should be encouraged but never forced to talk about their own experiences with those close to them. "

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

"Continue to provide Free TAFE, include the peer work course in this as soon as possible. Placements need to be available, not only to university students but to TAFE students as well. For this, organisations need to be prepared to take on more students as numbers will quickly grow. Conditions such as paid mental health days are essential due to the nature of the work and to avoid fatigue. As most mental health workers currently receive around the same as most retail workers, a higher wage could be useful in attracting people, as there are qualifications and a much higher risk to both mental and physical health involved."

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?

"Each person is different in what they want to achieve, but I believe that if we look at each client's individual aspirations we can find ways of realizing the opportunities they want to reach. In this way, it is best to remain focused on listening to the client, again providing continuity of care when wanted or alternatively a change in doctor when necessary. Additionally, by providing paid mental health leave from work when people require it, along with the option of keeping a job held without pay if a longer time off were required, during which people could be supported by centrelink on sickness benefits, people living with a mental illness would not be so apprehensive about looking for work. As someone who is now working part time while studying, I would have been better off financially to put more effort into proving I was sick and take the time I needed to heal. Instead, I was not even assessed by centrelink for disability support because I was able to work 15 hours. While I understand that there needs to be a cut off point, as this money is for those who need it, I had gone into debt while being visited by the CATT daily, unable to leave the house as a result. I had got the job after giving up on any help from centrelink, as I had already waited 6 months and was about to lose the unit I was renting."

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?

"Free and accessible psychiatry, as well as a full range of other services, along with better choice for clients and patients. "

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

"Educate and inform the public, along with new students and existing health workers, including doctors, in order to solidify and bring together any ideas and improvements that are implemented. If these services are going to be useful, people need to know about them."

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

"With a wealth of personal experience, there is so much more I would love to share. Please call or email me on my given contact details for more information."