

██████████:

Carer Submission

Your story:

I am ██████████, 54 years old and I am a carer and mother.

I also struggle with crohns disease and lupus, and I have to balance that with caring for my daughter as well as elderly parents (my mum has Parkinson's disease).

I have two daughters. The older daughter is 24. The younger one is 20.

I divorced from their father 17 years ago. It was obvious from the start that my younger daughter would have challenges. She had a range of challenges growing up, including global developmental delay, renal reflux and later she was diagnosed with autism too.

I knew that whatever her delay was, that I could make the best of it by getting her into activities that helped the brain connections. Through various activities including dance, she ended up catching up to her peers by year 10. She was doing 8 ballet classes a week and two VC subjects in Year 10 and had won academic and encouragement awards. Toward the end of that year, things started to fall apart.

Looking back, there were a number of triggers. She was coming up to her Cecchetti grade 6 ballet exams, which in the past didn't bother her, but all of a sudden she would have blanks in her memory. She found this incredibly distressing that her head was empty. She didn't tell me what it was till recently being three years afterwards. She can have a hard time explaining what's happening to her.

She had a breakdown and I asked her what we needed to do to remove what was causing her stress. This resulted (with collaboration with her school,) changing some of her subjects and giving up dance classes. She was still having serious mood swings and violent outbursts at home. About six months after that she had a full on psychosis. I rang the school to advise that I felt something wasn't right and could they keep an eye on her. Within the hour, they informed that she had tried to climb the stadium and jump off. She was admitted to the ██████████ Unit at ██████████ Hospital for youth still attending school. She was there for two months from June to August 2016.

Since then, we've been on a difficult road to recovery. We were referred from ██████████ to ██████████ RAPP unit (Recovery and Prevention of Psychosis) The first eight months were very difficult, as we had a lot of staff changes, and it left us in a position where we weren't being supported. After that we had the same case worker, but the psychiatrists and registrars changed often. The case worker seemed jaded and would not work with us as a family. My daughter was violent, and we couldn't get any help from ██████████ regarding the behavior and violence that myself and my eldest daughter were experiencing. They even said to us 'she's our client and they were there to help her, not us. It was hell.

That fundamental concept was the problem. If they had treated us as a unit, we could have coped a lot better and our family would not have been torn apart. She was only 17 years old.

Once she turned 18, it became even more difficult. They weren't listening to what I was writing to them and what was happening. I have an email where they wrote back to me, with regard to my not coping, with a cut and paste of numbers to call including Lifeline. It was pasted twice into the same response, leaving me feeling very unsupported and their message was like a sarcastic; tell someone who cares.

Over the last two years, we have got through one day at a time, and many of them, one minute at a time. I've done my best to manage the situation. There were times where I felt that the only time I

will get a rest from this is when I die. It was a dark scary time. We kept begging to be transferred to HeadSpace, as we had heard they treated the family as a unit, which was what we wanted.

It took us two years to be transferred, and it got so horrible and nasty. They demanded my daughter had to write a letter saying why she wanted to move. With the input of my whole family, we wrote a letter about why we were deeply unhappy. They finally discharged us three days before Christmas without the proper handover that had been promised, with nowhere to go. I believe this was purposeful.

I wasn't allowed to have any information, even for the NDIS, which I needed for the application. I pleaded with both her case worker (psychologist) and the team leader and was told, well you'll have to go through Freedom of Information. This was when I only had one more business day to collect information. I was in despair. The case worker sent through a report at 7.30PM on the Thursday, the day before Grand Final day and our meeting was on Monday morning. I couldn't believe how much unnecessary stress I was put through.

I was begging for support to help with the NDIS application process. I went to a number of organisations to get support to go through the NDIS application process, and they all said no. The case worker who had been very uncooperative, decided to come to the NDIS meeting. She made a recommendation for a School Leavers Employment Scheme, which attracted the majority of the funding. However, there are no programs available that Brianna can travel to by herself. We are trying to have that part of the funding reallocated to self managed so we are not locked into a program that is not located near us. Then we can use it for a local organization called Replay who can give one on one life coaching and training and they can come to our home. What they do is cheaper and more suitable.

HeadSpace has been a lot better. They listen more, and ask better questions. We've had the same psychiatrist seeing my daughter for an extended period, and he's been great. It is difficult that the reviews are only every 4 weeks, but this is better than the 3 monthly reviews at RAPPS.

There's still flaws in the system. I was meant to have a peer support worker, but she's been sick and now she's resigned. I believe this is just bad luck, but I am lucky that the family counselling done by futures in mind and helped us through. The psychiatric nurse practitioner has definitely saved our family and my life. It gave us an entirely different understanding. Our NDIS now funds this.

Dual diagnosis was a huge problem, in that her case worker, a psychologist from [REDACTED] didn't have an understanding of how the blend of autism and psychosis differed from those with psychosis from drug or trauma. Some hospital staff have said that they thought that she was "putting it on" to be admitted. I explained that a person with Autism can be very matter of fact and appear to be emotionless when talking about what they are going through. Often they did not understand and that led to early discharges, non-admissions and a horrible game of hospital ping pong.

My daughter has spent over 100 nights in hospital since last August. This includes the amount of nights spent in casualty and Unit 2. It is really wearing is both down. There has been times she's been discharged in the middle of the night or discharged from the unit with very little notice. We've had to deal with the many times she's run away. I have to commend the police and the ambulance and the PSO's at the train station who have helped us. There was one occasion where the police were able to get their Pacer Doctor to come, which was very helpful as they were able to pass on the information to the Emergency mental health team at the hospital. This cut down on waiting time considerably. Unfortunately other times the doctor was busy or it was too late in the evening for them to come. The police expressed frustration at this.

What I have learned:

- I understand that my daughter presents as a person that has had significant trauma, which makes them look to me, like what have you done to her. I have felt like I have needed to prove my sincerity, and my motivation.

- The trauma that she has had is from being over sensory all the time, and I believe this is what led to the psychosis. Her attempts to suppress her over sensory condition, has come in the form of psychosis. As a result, she now hears voices, and wants the voices and the torment to stop.
- I have had to change my life around, change jobs, and then give up paid employment altogether due to the time demanded to care for my youngest daughter. It's been incredibly difficult on me and the rest of the family.
- Now we know how to help her better by focusing on what she needs to do to feel safe and be safe. This sadly can mean that she is isolated, huddled under a weighted blanket in a darkened room with relaxing nature music and soft toys from her childhood. These episodes can last for days, which makes other appointments hard. Appointments are often better if they can come here. She usually feels safest here, but at times when her voices are really bad and she feels like killing herself to make them stop, she will call an ambulance or ask me to take her to hospital.
- On Wednesday her support worker comes, and they can go for a drive. She has grown to feel safe with this support worker and they usually get out for part of the time.
- For me, I am now doing work experience, which has been really useful for me to know that I can contribute. I do this when the support worker is with my daughter.

What I would recommend:

- There needs to be better information sharing between patients families and other medical staff, for the highest good of all concerned. I understand that some families may be the issue, but they must be able to determine whether this is the case. They have to ensure whether the family is a safe place for the client. A person cannot heal if they aren't feeling safe.
- The psychiatric nurse practitioner from Futures in Mind has been a lifesaver. She was recommended by my daughter's school. She has a comprehensive understanding of the issues and gave us practical strategies that worked. Some of these were from Beacon House in the UK and I have attached a summary which we found life changing. She was there for us over the difficult Christmas period. She helped fast-track us into Head Space, and made an incredibly difficult situation better.
- Understanding trauma has been critical. Knowing how to help my daughter feel safe has been the best management strategy we have found, and this has come about through a strong information base.
- Sometimes she can feel the "badies" are in my body. I recognise when that's going on, she needs to be with someone else, and that may mean she needs to go to hospital. But it is a shame there's nothing in between hospital and at home.
- YPARC (dandenong) - youth prevention and recovery centre - has been fantastic, but it only has ten beds, and it needs a lot more resources. 10 beds for the huge area of Cardinia, Casey, Greater Dandenong and Monash. The intake and waiting list is long and difficult. Nowhere near enough beds. Having something like that which also had a lock down aspect would be so very helpful for people who are suffering psychosis need to be prevented from running away. When people are suicidal, it's very difficult to find somewhere for people to go. Thankfully, my daughter asks to get help and goes to hospital.
- There also is not enough beds dedicated to Mental Health in the emergency department at ██████████ Hospital. Currently there is one bed and three reclining chairs to cover a huge area over City of Casey and City of Cardinia. We have spent so many hours waiting to be seen.
- The team that was previously known as CAT (Crisis Assessment Team) have now changed their title to the Psychiatric Triage team as they advised me, they are not there to deal with Mental Health crisis situations any more. We need to change this back to a team that can make visits and do assessments at homes.
- I would like to mention that the school was very helpful, supportive and adaptable in helping my daughter get through to finish year 12. They focused on my daughters mental health and wellbeing and were able to give her credits for what she had achieved in earlier years. She was not well enough to sit any exams and together we got through. I am very grateful for the incredible welfare team (who were very under staffed) and the dedicated sincere teachers.

- I have been to many education sessions provided by Uniting Care, Ermha and Alfred Health. Without what I have learnt in those sessions I don't think we would have got through. I am saddened to learn that their funding has now run out for such sessions. It would be great to reinstate those programs.
- Cognitive Behaviour Therapy (CBT) does not work for people on the autism spectrum. Once they have gone into a primal mode of fight flight freeze or submit. Treatment needs to be around understanding this and how to ground someone when they're in that mode as there is no logic in their brain at that time. It is disconnected and cannot reconnect until they feel safe, calm and settled. This can also be true of some other people who have suffered PTSD or other trauma as they jump to primal mode much quicker and CBT goes out the window. When we learnt this we now focus on what makes my daughter feel safe.

Ms [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]