

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

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

"Running Youth Mental Health First Aid courses in schools, and Mental Health First Aid courses more broadly. Treatment of patients on an equal footing with those who have other medical concerns"

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?

"Earlier recognition of emerging symptoms - better training for counsellors, psychologists and GPs. More than 10 appointments under Medicare and no gap payments. "

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

Better education in the community of how to support someone who is experiencing suicidal thoughts - again this can be done through Mental Health First Aid programs. Not being sent away from emergency departments or left for hours in the waiting room of emergency departments. Faster triage and longer inpatient and follow up support.

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.

See attached submission

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

See attached submission

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

See attached submission

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

See attached submission

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?

See attached submission

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?

See attached submission

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

See attached submission

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

See attached submission

I started this submission answering each question in order, and found it too hard to articulate the issues faced over the last 10 years with the mental health system in this format. To enable me to recall all the barriers and issues, I need to tell this story in chronological order. It helps make sense of where the system failed our family, our level of knowledge of the system at different points and how that worked sometimes for and against us. I think it also has more impact in articulating the level of distress our family have endured during this period.

We have three children, and for the purposes of this submission I will give them each an alias. Emily 24, Rose 22 and Will 15. Emily's current diagnosis is schizoaffective disorder, Rose's diagnosis is borderline personality disorder and Will – not diagnosed but at 15 seeing a psychologist for low mood.

My husband and I are both tertiary educated in professional roles. Our story demonstrates that no level of education or income helps navigate this broken system and get the support and treatment our children deserve.

Let's start with Emily. From an early age she had difficulty making friends and some episodes of extreme emotions and on occasion sensitivity to sounds, tastes and touch. She experienced bullying from within her friendship groups. She wanted to be social, but didn't know how to fit in. She always felt more comfortable with one best friend than negotiating a group. **Q: Should early educators and teachers be trained in early signs of anxiety and mood disorders? Would this have led to better support of Emily from a younger age?**

In high school, Emily's behaviour become more difficult, and she was starting to get in trouble at school. She was a good student, but only excelled in subjects she enjoyed with teachers she liked. On moving to a private school in the country with a new but small friendship group, things settled for 18 months, although with some social anxiety issues still impacting her enjoyment of school. She started seeing a psychologist (year 10). A major blow up at a friend's house led to lost friendships, bullying by the rest of her year level and eventual move to another school. **Q: Are psychologists properly trained to identify more serious mental illness developing? Should they be able to refer clients to a psychiatrist? Would this have led to an early intervention in what developed into a serious lifelong illness?**

Year 11 – anti-depression medications prescribed by the local GP. I understand now that anti-depressants should be carefully administered to young people, as they can result in suicidal thoughts and ideation. **Q Should GPs be able to prescribe these medications to young people without a psychiatrist review or oversight? Would our daughter not have had a suicide attempt if she had not been prescribed these medications at such a young age?**

In year 11 a cyber-bullying episode resulted in attempted suicide by pharmaceutical overdose. Emily was taken by ambulance to ██████████ Hospital and seen by a CAAT team. She was discharged within 24 hours with no handover or information on what to do next. I took the week off work to provide support expecting a call from a youth mental health worker, the silence was deafening. I organised

an emergency appointment with her psychologist and began my first foray into the mental health system. I tracked down the person that should have contacted us from youth mental health services and found out that in [REDACTED] the youth mental health program had a visiting psychiatrist one day a fortnight, the next available appointment was in three months. We stated that we could easily take her to [REDACTED] for an appointment, but were advised that we weren't eligible to see a psychiatrist in [REDACTED] as we lived in [REDACTED]. We hung in there for three months, and upped her psychologist appointments to weekly. The appointment with the psychiatrist lasted 10 minutes – Emily didn't see the point, the incident was three months in the past. She didn't identify with having a serious mental illness that needed psychiatric treatment. As a 16 year old female, she did not feel comfortable talking about her issues to a male doctor. The mental health service happily gave up on her at this point, despite us still being seriously concerned. **Q: A barrier to help is self-awareness of issues and illness. The Youth Mental Health First Aid course is a great educator and tool. This could and should be provided to all school students, teachers, parents and doctors. Would my daughter have engaged more in treatment if she had received mental health education at school? Why do service providers give up so easily, is it due to caseloads and ability to resolve the easy cases and meet targets? Due to low numbers of psychiatrists in rural areas there is little choice, which is another barrier to getting help.**

Growing anxiety at the end of Year 11, signs of paranoia and auditory hallucinations emerged for Emily. We didn't identify these symptoms at the time, hindsight tells us that these symptoms may have been hypomania or psychosis. Our focus was getting her through her one VCE exam, which she passed with a good mark. Sadly this is her highest academic achievement due to her illness. Serious mental health issues started to escalate from this point. Use of marijuana began at this time – possible self-medication to deal with the persistent anxiety. **Q I refer again to programs such as Youth Mental Health First Aid which would have assisted in all of us recognising psychosis.**

We pursued a psychiatric assessment at this time with a private psychiatrist given our poor experience with the public system. Local GPs had no idea to who to refer to, with few private providers in the region.. We decided to see a psychiatrist in Melbourne who had seen our niece. Her speciality was youth and ADHD, and she diagnosed Emily with ADHD and prescribed Dexamphetamine. (Use of Dexamphetamine arguably caused a later manic episode). **Q: Should a serious mental health illness diagnosis be peer reviewed before these medications are prescribed? Should the use of these medications be more closely monitored in young people? Do psychiatrists have an unconscious bias to their speciality area?**

The Dexamphetamine did help Emily with concentration, we thought we were onto something. However during this period she attempted year 12 twice, both times starting enthusiastically, but the usual social anxiety and issues with friendships, risk taking behaviour and poor decision making resulted in drop out after one term both times. She managed to hold down part time jobs in cafes, and once she turned 18 started work in a night club. Her behaviour started to become more erratic and bizarre. Paranoia and auditory hallucinations were more frequent. Regular couch surfing and disappearing for days, regular use of marijuana, erratic sleep patterns also a result of working nights and using Dexamphetamine medication. She decided that she needed to revisit use of anti-anxiety medication – we found another psychiatrist in Melbourne who specialised in youth.

After 3 appointments with the new psychiatrist the doctor concluded that Emily didn't need medication, just talk therapy. The psychiatrist did not meet with family members to hear our concerns and observations, had she done so she would have heard us describe symptoms of hypomania (not that we knew what hypomania was at the time but we were observing rapid speech, auditory hallucinations, paranoia). 3 months after being told she didn't need medication, my

daughter experienced her first manic psychotic episode. **Q: talking to other family members is critical to diagnosis, but families are often dismissed or ignored. Someone with no insight or who is scared of their symptoms will hide them and not always express them to their doctor, resulting in an inaccurate or missed diagnosis. Talking to family members should be a mandatory part of assessment and diagnosis. Would my daughter have been saved her first hospitalisation if the doctor had taken time to talk to us?**

Our first experience of a manic psychotic episode was I understand at the high end of the scale (like a 7 on an earthquake Richter scale). On a Friday afternoon, Emily's social media was getting a hammering. She had announced a pregnancy with her new boyfriend and that she was going to have a drink to celebrate. Facebook trolls started criticising her for talking about drinking while pregnant. I met her and her boyfriend for dinner to celebrate with them (without the drink). She seemed up – but that could be the excitement of her news, her speech was rapid, her thoughts racing (all terms I now know are related to hypomania), she hadn't slept much, but the weather had been very hot and this was not unexpected. I went home assured that everything had settled down. Later that night things escalated, Emily thought she was having a miscarriage, and that she had seen the fetus in the toilet. We organised her to get to the Women's Hospital, and her grandmother who was a neo-natal nurse met her there for support. All tests came up negative for pregnancy, but she didn't believe them and became more and more agitated. Social media went off again, with her posts about losing a baby, but actually being pregnant with twins, she thought one had survived from her reiki healing. The next day things became worse, twins turned into triplets, reiki healing each new fetus discovered and naming them, social media was in meltdown, and on this day she changed her name (which she has kept ever since). She started writing short rhyming poetry (another sign of mania). During it all she also managed to slam her thumb in the door, popping her nail off without feeling any pain.

I have described this episode in detail, as it is important to understand what families deal with during a major psychotic episode, the level of danger of harm to everyone, how distressing and frightening it can be.

Her grandmother called the CAAT team who visited on two occasions, but they didn't organise an ambulance or other transport to hospital. On the CAAT team's advice I drove back to Melbourne and took Emily myself to ██████████ pretending that we were getting her thumb nail treated. On the drive she spoke of healing the world, going on the Voice to sing at a pitch that would heal people, that she would be famous and sell these healing records. We spent 30-45 minutes in the emergency waiting room where she reiki healed other patients and was difficult to contain. Being my first experience of these manic symptoms, it was quite distressing for me, with my main concern that she would bolt out the door, harm herself further and not get treatment. **Q Should patients who are experiencing psychosis always be transported by ambulance or with a CAAT team to ensure they are safe and contained? Should patients experiencing psychotic symptoms be fast tracked in triage, and managed in a different area for the safety of themselves and others?**

Once in the emergency area, I spent over an hour chasing Emily in and out of her assigned bed, the bathroom and everywhere else while we waited for a psych assessment – again I was fearful that she could harm herself or others. It was very stressful and distressing for both her and I. On finally seeing a doctor, they quickly assessed she should be admitted involuntarily. This was our first experience of an involuntary admission. Very little time was spent explaining the implications of this to me as her parent and carer. We had no idea about high dependency units, how we could contact her, visiting hours and rules.

Our experience here and elsewhere is that not enough information is provided to families, particularly first timers to the system. They also forgot to contact us to organise a family meeting early in her admission, which I was advised was normal protocol. It concerned me that if they forgot to follow their own protocols in this regard, what else were they missing in the treatment and care of our daughter. It all seemed very random and subject to the memory of staff and poor communication on handover of patients and files.

Q What support and information should be provided to families and carers during an involuntary admission. Can this process be better resourced to ensure families have the information they need in a timely manner? Can they use checklists to ensure that all the information has been provided, family members contacted and a meeting with the treating team arranged? What is in place to ensure a proper handover occurs at shift changes?

You would never choose ██████ for a very sick, first time admission into a psychiatric ward for a vulnerable young 19 year old girl. The other patients were mainly 30-40 year old men, who were too interested in befriending our daughter. One mania symptom is over sexualised behaviour, being in a ward with men put our daughter at risk of sexual assault. On a subsequent admission to ██████ she was in a female only ward – I don't believe this is new, but perhaps on her first admission there were no beds available in that ward. **Q is it better to transfer patients to the most appropriate facility, ie in this case a female only youth ward? Should each facility have more segregation between males, females and young people?**

██████ is an older facility and is not set out well for supervision of patients. We were concerned on many occasions as to our daughter's safety, particularly given she was so vulnerable, unwell with no insight to her illness. The side effects of her medications made her very frightened, as they were heavily sedating and on one occasion she had difficulties walking. It was her first time on serious medication such as Lithium and due to the staffing levels she didn't feel well supported or informed on how these medications would make her feel, how long they would take to work and how long she should be in hospital. We fought hard to get her discharged given the level of distress she was experiencing, in hindsight I would say she should have stayed in longer, although only in a safer more therapeutic environment. **Q wards are under staffed, some staff lack the training required to support seriously unwell patients, staff spend too much time in the nurses station and not on the ward, too many interns with high caseloads and not enough experienced psychiatrists to support patients or families. I also note that during her admission they didn't arrange any medical care for her thumb nail, our experience to date in mental health wards is that they rarely arrange medical care for other injuries or illness unless life threatening.**

On discharge, she moved with her boyfriend to the Western suburbs and therefore out of the care of the CAAT team and doctors at ██████. Here is the next issue, young people move a lot, particularly if they are at early stages of mental illness and can't hold down a job, have volatile relationships with family and friends. This can result in lack of continuity of care, and ineffective treatment. In Emily's case, she infrequently saw her case manager and slowly stopped compliance with her medication. Needless to say, her symptoms started to re-emerge within 3-4 months of discharge. **Q how can we improve continuity of care. Young people move a lot, particularly if they are in unstable relationships and unreliable work. Their care should be more flexible to move with them or better handover occur. Case workers in busier areas (metro) don't follow up on clients that won't engage, they deal with the easy ones, and patients in the too hard basket too easily slip through the net. This is where some regional areas actually outperform metro services, we have found the case workers in ██████ / ██████ to be very supportive and persistent, including making house calls.**

With the re-emergence of symptoms, Emily's relationship broke up, she moved back home to [REDACTED]. She was assigned a caseworker from the youth mental health team, who followed up regularly and assisted with trying to get her back on her medications and bring down her rising mania. I was invited to attend an assessment with a psychiatrist, where we were discussing a possible hospital admission if she didn't comply with medications. Emily became very distressed, particularly with the barrage of questions from the psychiatrist. While I took her outside to calm her down, and devise a medication compliance plan with her caseworker the doctor signed off an involuntary treatment order. I was not aware that a previous doctor had already started this process, and this was the second assessment under the Act. I felt completely blindsided. I felt that Emily was improving slowly and we were able to support her to take medication at home and a hospital admission would send her backward. **Q: More consideration needs to be given to family input into treatment and they should be informed if not consulted when a treatment order is being considered. In this particularly scenario, I believe the doctor breached the mental health act. Once someone is admitted, the process to challenge an involuntary admission takes as long as the 28 day order, so there is no point in making a complaint.**

Within 24 hours of admission to the [REDACTED] in [REDACTED], Emily's symptoms escalated as a result of being in a chaotic environment. Due to her distress she shifted from agreeing to medication to refusal. She was physically restrained to administer medication by injection. In doing this the staff reinjured her knee, which had been operated on 12 months previously. During her admission, she was unable to see a medical specialist for her knee, despite not being able to bear weight on that leg. **Q: Hospital staff should have the training and skill to administer medication without having to resort to such force that a patient is injured. Had a full medical history been taken so that staff were aware of other medical issues, family should be involved, particularly when someone is unwell and can't pass this information on. Why can't patients in a psychiatric ward receive general medical care, it seems ridiculous when they are in a hospital that they can't attend other medical appointments or allied health services?**

During this admission, she also had a major panic attack after receiving one of her injections. She thought she was having an anaphylactic reaction to the medication, and seriously thought she couldn't breathe. We were only alerted to her distress from another patient calling us, my husband (a paramedic) and I went straight to the hospital and found her lying outside under a blanket, being comforted by the patient that called us, not a nurse in sight. In fact the nurses were almost mocking her for being ridiculous. We managed to calm her down and return her to her room.

This hospital admission was traumatic in so many ways. I made a complaint to the hospital and the mental health commissioner and after Emily's discharge, made an informal agreement with the hospital that she was not to receive treatment there again. The complaint handling process at [REDACTED] Health was inadequate. After escalating my complaint we eventually managed to arrange a meeting with the Head of Psychiatry some months later who apologised to Emily for her treatment. This apology went a long way for helping her move on from this traumatic experience.

Emily had lost most of her friends after this admission, 19-20 year olds had all moved on, were working and studying. The social isolation was crippling for her, and after what had technically been a six month manic episode, she was in the depths of depression. Her case worker visited once a week, but there were no other services offered to her. No psychologist, psycho education, group therapy – any therapy. Long boring lonely days of depression. Social media was her one outlet, and she managed to keep in touch with some friends, but less helpfully with ex patients from her

admissions to [REDACTED] and [REDACTED] Health. Q: There are virtually no public mental health services other than acute care and case management in regional Victoria. Patients will continue to go in and out of acute care if they don't receive other therapies. Where is the CBT and DBT programs – these seem only to exist in Melbourne, at great cost and mostly in the private healthcare system. More recently, service providers such as Mind Australia are only able to provide services to people on NDIS – getting onto an NDIS plan is virtually impossible. More about that later.

To break the social isolation, Emily disappeared down to Melbourne one to visit a "friend" who she had met in [REDACTED]. After 3-4 days with no medications, and escalating manic symptoms evidenced through brief phone conversations and texts. We reported her missing to the police, who were next to useless in helping us find her. She wasn't on a treatment order, and we have since learned the value of CTO in getting her tracked down by police and returned to care. I managed to work out where she was through transactions on her bank statement and narrowing down who I thought she knew in that location. Her friend by now realised she was completely psychotic, and at great risk of harm. I listened to her rant and rave with sounds of traffic way to close, while my husband spoke to police and ambulance as they closed in on her. She was involuntarily admitted to the mental health unit at Ballarat Hospital that night.

Ballarat ACU was a revelation, a well-designed nurse's station that provided good sight lines to the whole facility. I felt that she was safe here compared to [REDACTED] and [REDACTED]. All mental health facilities should be designed to assist in the safety of both patients and staff. The new facilities at [REDACTED] Hospital also have better sight lines than the [REDACTED], although still not as well designed as Ballarat.

During her admission at Ballarat we explored for the first time the option of private health treatment. I spoke with the treating doctor about facilitating a transfer as we had private insurance. I was pretty shocked to learn (and have experienced subsequently) that there is no treatment pathway from public to private hospital. The public psychiatrists can't write a referral and patients can't easily get out of the ward for a GP appointment. We also discovered that our private insurance didn't cover mental health treatment anyway, and there was a two month wait period to upgrade our plan (I think this has now changed under federal legislation). Q; how can we improve the pathway from public to private to reduce the caseload on the public system for patients that can be adequately treated in the private system?

Emily settled more quickly after this episode with a slight change of medication from Lithium to Valproate as her main mood stabiliser. Over the course of the last 5 years she has been on every anti-psychotic and mood stabiliser on the market. Each doctor feeling like they can add value by changing her medications. This has not been a controlled experiment, and very frustrating for our family in helping her with medication compliance. Q: changes to medication should be better controlled and monitored. Why is it such a guessing game, why do they experiment so wildly? Medication changes in hospital should involve more input from the psychiatrist treating a patient in the community.

I explored natural therapies at this point and found Emily a local psychiatrist who treated her for pyrolles (an unaccepted diagnosis in the medical world that is linked to mental health). She started taking specially formulated doses of zinc and magnesium that seemed to help lift her mood. Combined with her regular medications, this began a rare period of stability for Emily. She managed to complete a massage course, start a part time job at a local café, this lasted for about 5-6 months and we thought all was on track for recovery. With a diagnosis of bipolar, we were aware that symptoms were episodic, and perhaps she was in a long period of remission. Q is pyrollia real,

should there be more scientific research to support this treatment option, there is some compelling evidence of efficacy of zinc and magnesium in managing mental illness symptoms.

Lack of sleep one night led to hypomanic symptoms displayed at work. Her employer sent her home, and embarrassed she never returned to that job. Next came a spontaneous decision to move out of home with some friends resulting in lots of partying, late nights, and she stopped taking her medications again. She was caught driving erratically, lost her licence for drunk driving, and a few weeks later her concerned friends sent her to the emergency department on Christmas Eve. Emily has never quite managed to get her licence back since this incident which is another barrier to work and study. She did get an interlocker installed in her vehicle, but due to another hospitalisation, she lost the continuity of testing, and needs to start the process over. This is a difficult and costly exercise for a young unemployed person with a mental illness. . Q Emily has been offered little help from her case worker in regards finding and keeping employment. No service provider has been recommended. People with a mental illness should be able to access special work placement and support programs that help them negotiate special conditions. Special consideration given to people with a mental illness in regard traffic infringements and re-licencing.

Emily negotiated an admission to yparc rather than the [REDACTED] Health [REDACTED] given her previous traumatic experience there. This was a good outcome and resulted in a shorter stay.

Yparc is an excellent facility, which [REDACTED] is fortunate to have. There should be yparcs in more areas across the State. It is a more appropriate treatment option for young people at risk who are not so acute as to require an involuntary admission. Yparc is run by Mind Australia, provides life skills, workshops and therapeutic activities such as cooking, art therapy, movie nights etc.

This story is now early 2016, two years after Emily had her first psychotic episode. In two years she still had no insight into her illness, had received no therapy only medication, with doctors stating she was too unwell to receive therapy – but I query if she was well enough, where would she receive that therapy anyway? She turned often to her own form of therapy using psychics and tarot card reading. When modern medicine fails you, the only place to turn is to spirituality and she has explored this in many ways and forms over the years. Sometimes useful, sometimes detrimental, increase in interest usually indicating an escalation in manic symptoms.

2016 we start a new chapter of mental health system experience, with our second daughter Rose revealing she had an eating disorder, possibly bulimia or anorexia and that she needed help. Rose was a high performing student, studying at Melbourne University at the time. She had complained of stomach issues for 8 months and had seen a specialist in Melbourne who had tested her from head to toe, and concluded that she may have a mental illness rather than a gastric one. Rose's mental illness is likely a combination of genetics and the impact of living with her sister whose mental health symptoms were confronting and frightening. Q should there be counselling and support for all family members when a serious mental illness is diagnosed within the family to ensure everyone's mental health is considered and managed.

Rose sought out a therapist specialising in eating disorders and started following a recovery plan. However after a few months she admitted that she was also experiencing symptoms of depression and having suicidal thoughts. We upped our private health insurance in anticipation of seeking an admission to a private facility (after our poor experience with the public system) and commenced the referral process to a private psychiatrist. This process took longer than she could bear and she took an overdose spending a night in emergency at the Royal Melbourne Hospital. She was discharged within 24 hours and still no admission finalised to a private facility. Q there are too many

delays and barriers to getting treatment when needed. Why are people who attempt suicide not held longer at hospitals, and admitted to psych wards, if they have private insurance why can't a transfer be organised without at risk people being sent home to bewildered family and friends?

We finally managed an admission to [REDACTED] where Rose undertook a 2-3 week general program and prescribed a range of medications to stabilise her mood. She then began their highly regarded eating disorder program. We have two other nieces that have had eating disorders, neither have private insurance, neither have received adequate treatment for their illness due to restrictions in the number of psychologist visits through medicare, and very few inpatient programs for public patients. Q There needs to be more access to inpatient eating disorder programs for everyone, not just those that can afford private insurance. The federal governments change in policy to allow 20 appointments for eating disorders is welcome. But why only eating disorders? What about other serious mental health issues such as schizophrenia and bipolar? Regardless of the number of appointments allowed under medicare, there are still many families that can't afford the gap payment.

While Rose was in the [REDACTED] we decided to see if an admission there would also assist Emily given our private health insurance qualification period was over. There are two major issues that arise from inpatient care. Both of our girls met people who would impact their lives negatively while in hospital. While Rose recovered from her eating disorder, she learnt a lot about self-harm, beginning a relationship with another patient that saw her lose another year of her life to self-destructive behaviour. Q: how can hospitals deliver the intensity of treatment required for eating, personality and mood disorders while reducing the impact of relationships developed with other patients?

Emily proved still not well enough to engage with any meaningful behavioural treatment at the [REDACTED] and managed only to get two other patients kicked out for breaking the rules, and herself kicked out within three weeks. She met a drug rehabilitation patient, who introduced her to ice, and so the next chapter of her struggle with her mental health became complicated by frequent bouts of drug induced psychosis and numerous hospital admissions to the Austin, [REDACTED] and [REDACTED]. Q should drug rehabilitation programs be run in the same location as other mental health treatments were there are other vulnerable patients?

The eating disorder program at [REDACTED] also ran day programs for outpatients which Rose attended on discharge. The discharge process ensured that she was ready to step back out into the world, but as with most patients, this required a few re-admissions before she was able to make a final step away from inpatient and utilising the day programs offered. Q all programs need to acknowledge that patients will need to attend more than once, and should have a different stream or intake for repeat admissions.

Whilst Rose's eating disorder treatment was very successful, she developed a relationship with another female patient who had not recovered and was still at significant risk of self-harm. Her girlfriend had many re-admissions during this period, after suicide and self-harm events resulting in numerous trips to various emergency departments. The two girls seemed to oscillate between one being suicidal and the other supportive and back again. The [REDACTED] staff and doctors did not want to admit the girls at the same time, and at one point Rose had to seek treatment at another private hospital. This admission was a disaster, the psychiatrist assigned to her changed her medications immediately (my earlier point that psychiatrists do this too often without consulting the previous treating doctor) The rapid change in medication had an immediate negative impact on Rose, who felt betrayed and let down by the system which she had gone to for help. Q when

someone feels unsafe and suicidal, there has to be a better and urgent level of care that they can access without going through referrals and a long admissions process. Emergency departments can't treat them and will send them home. Is there an option for a rapid intake, 2-3 day stabilisation admission to help people settle and connect with appropriate services?

During this period Emily was back living in Melbourne with her grandmother and being case managed in Heidelberg. She had an admission to the Austin hospital which I recall had a mental health emergency triage that did exactly as I am suggesting above. It wasn't for long term care, but enabled short term care for patients who had attempted an overdose or were suicidal. Both our girls have been admitted to this section of the Austin and found the environment to be safe and calming.

On Christmas Day 2016, Emily was irritable and erratic, her grandmother thought it would be better if she came home with me to give her some respite. I was concerned about driving 1.5 hours with her in the state she was in. While driving at 110 kms/hr she became seriously psychotic and wanted to injure herself by getting out of the car. As a precaution I had locked the car doors, delaying her action and allowing me time to slow the car down. I drove straight to the [REDACTED] police station, only to find no-one there. I spent ten minutes wrestling her to the ground to stop her running in front of traffic while we waited for police and ambulance to arrive. An admission to [REDACTED] and transfer to the Austin (near her Grandmother) 2017 was a year of many psychotic episodes, ambulance, police, hospitalisations. **Q: this was a serious psychotic episode, how are families supposed to manage someone in this state? Is treatment in the community appropriate when someone is so unwell? There are few options for long term treatment for serious mental health conditions other than acute wards.**

Christmas 2017 – Emily was reasonably settled back at home, doing pretty well, complying with medication. One of her spontaneous outings resulted in a 3 day disappearance with friends, drug use, lack of sleep and serious psychotic episode. After another admission to HDU and AAU we discussed with her doctors if the Extended Care Unit was an option. Naively I thought this might be somewhere she would get some psych-education, that we could organise some behavioural therapy. In the three months she was in ECU, she was given a lot of medications, didn't participate in anything and for the first time gained significant weight due to the heavy dosage of drugs prescribed, lack of activity and lots of uber-eats due to the inedible hospital food.

Q: This demonstrated to us again that there are no long term secure care facilities that can assist in treatment of serious mental health conditions. They are simply containment areas that ensure compliance through sedation.

On discharge from the ECU, Emily attended yparc as a step down, but absconded within days with an ex ECU patient and re-presented to hospital with psychosis again. Over the next few months we went through a cycle of discharge and readmission. We had decided that due to her drug use and increased incidents of psychosis it wasn't safe for our 14 year old son to have his sister at home. This challenged the system even further, we soon discovered there are few social housing options. Service providers undertook assessments (when she would allow them to), and deemed her too high risk for their housing. She was at risk of homelessness if she was discharged. **Q: there needs to be more supported housing for young people with a mental illness that is not subject to so many barriers and rules**

In 2018 it was recommended that Rose complete a DBT course which is recommended for Borderline Personality Patients and PTSD. The waiting list for DBT through the private hospital was

long, and the course itself is 40 weeks. Rose wanted to get on with her life and skip the waiting list so we enrolled her through the Melbourne DBT program that had no waiting list, but as it wasn't through a private hospital wasn't covered by private insurance. 10 weeks was covered by the 10 visit mental health plan, we paid the gap of 30 weeks. **Q these programs are so valuable for recovery, and should be fully covered by medicare and accessible to everyone, not just those that can afford them.**

During 2018 ██████ Health did not have a full time psychiatrist in the ACU and Emily saw a number of different doctors. One of them decided that he would experiment with ADHD medication (revisiting an old diagnosis) and reduced her mood stabiliser medications and put her on ADHD medication. He discharged her to yparc, against our advice as we felt that she was too unwell, erratic and irritable. Her behaviour escalated at yparc, she was abusive to staff and she ended up again dragged back to hospital psychotic and very unwell.

We were at our wits end at this stage and put in a complaint via the Minister for Health (██████) to the CEO of ██████ Health. The use of locums in the ACU was not helping our daughter, who had seen 6-7 different doctors in 4 months. They made some changes which resulted in her seeing one doctor for 12 weeks, and a decision to try her on Clozapine – the drug of last resort for treatment resistant patients. **Q this demonstrated the importance of continuity of care. Regional hospitals must be assigned permanent psychiatric doctors and not be reliant on locoms.**

This drug worked really well for Emily and after nearly 11 months of hospital treatment she was the best we had seen her and she was discharged to the CCU – Continuing Care Units – which are supported living units. Clozapine needs careful monitoring, two missed doses results in restarting the medication at a lower dose, so the CCU seemed like a great option for supervision of medical compliance.

All was going well until we entered the usual cycle of boredom – the CCU staff couldn't engage her in any activities, and she was not following the rules of the CCU, 2 day disappearance, medical non-compliance and re-hospitalisation. She also lost her place at the CCU as a result. **Q most of the public facilities lack programs for patients, there should be art therapy, yoga/mediation, walking groups, music therapy etc.**

After this latest admission we finally got through the assessment process for Emily to attend the ██████ Program (AOD program) run by ██████. The Clozapine definitely made this possible, with her concentration and mood much improved. She was discharged from hospital directly to this six week program and made it through almost to the end. Three days before the end of the program she had an interaction with a staff member that became heated and she was kicked out before she could finish the program. On discussing the incident with other staff, they felt that the staff member could have done more to deescalate the situation. **Q I have seen many program and nursing staff not adequately trained in dealing with some of the difficult behaviours of people with a mental illness. The patient gets punished and blamed for their behaviour which can often be detrimental to their treatment and recovery.**

We were hopeful after the success of the ██████ program that Emily could come home and start looking at working or studying again. She organised an assessment for the 3 days/week at the ██████ day program. She had an AOD counsellor visit weekly and her case manager also. I tried to organise work experience at a local café. She also signed up for one of the free tafe courses for the second semester.

However, the 3/day [REDACTED] day program never happened (I'm not sure why), the café were having staff problems and didn't feel it was the right time to take her on for work experience, and the tafe course didn't start for months. She tried two evening short courses, but found the cohort were all older women. The usual boredom set in, an opportunity to catch up with an ex-patient, led to a day away from home, missed medication, a random meeting of some people that led to drug use, theft of phone, psychosis, another hospital admission.

We have talked to her case manager and others about getting her into the Dual Diagnosis Unit. We were hopeful that this would provide AOD education and CBT – we now hear that it is full of heavy drug users and not the right environment for her. **Q Dual diagnosis is much needed treatment as many people with a mental illness turn to drugs to treatment systems. There are not enough DDU beds available in Victoria, and there should be different levels of care so that heavy drug users are treated separately from others. DDU should fall under compulsory treatment orders. Currently any drug related treatment is voluntary**

So here we are again, ACU, yparc, nothing planned for discharge, no psych education, no therapy, nowhere to go for other treatment, a likely return home, no job or study, boredom, misadventure we start the cycle again.....

In the meantime, Rose's own mental health has been deteriorating, she is feeling suicidal again, is looking for a short hospital admission. Is battling the referral system with a GP that wasn't able to properly write up her symptoms, or make suggestions of treating psychiatrists or hospitals. Her referral was knocked back by the [REDACTED] (no reason given – are they too busy, or did the GP not make a compelling referral?), she requested the GP send the referral to two other hospitals and she received push back from the receptionist about too many referral requests and having to come back in and see the GP. How hard does it have to be to make a simple referral and get treatment when you need it? The receptionist and doctor seemed to have no care or understanding of Rose's previous mental health history and that when she says she is having suicidal thoughts she is at serious risk of harm. Beyond frustrated and upset.

At the start of this submission, I stated that it was important to tell this long, sad, frustrating, dispiriting story to help the Commission and others understand how hard it is to get adequate, useful, long lasting treatment for serious mental illness.

People with personality and mood disorders need to receive long term care in a contained therapeutic environment. This cannot be provided in a hospital environment nor in the community. They need treatment in a facility that is safe and secure, with an outdoor garden and greenery, with activities and programs including behavioural therapies. These facilities exist, they are private and expensive and not covered by health insurance. Ironically they cost the same as both a public or private hospital at between \$700-\$1,000 day. The State Government spent over \$300,000 on inpatient care for my daughter last year, and over \$500,000 over the last 6 years for zero result. She could have had a year of personalised care in a private mental health retreat instead, supported by caring staff, activities and behavioural therapies.

The NDIS is now diverting any community mental health services that did exist to NDIS clients only. Getting NDIS approval is extremely difficult, particularly for mental health, as there seems to be limited guidance on assessment for mental health disability. It has taken a year for us to get an approval for Emily. We are yet to meet a planner, and we understand that making a plan and getting a budget is equally long and painful as getting approval for the scheme. I find it offensive that the

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Federal Government keep stating that the uptake of the NDIS has been lower than expected giving them a better budget position. When it is lack of approvals and access to the NDIS that is keeping the cost down. In the meantime, mental health services are no longer funded.