

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

SUB: 0002.0028.0237

## Name

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

"I feel it is better for 'common' mental health issues, though there is still a long way to go. More hard core issues still receive mixed reactions within the community. Homelessness driven by mental health, people that are a danger to society. A lot of people suffer mental health issues in silence. People are all understanding about those, because it may not affect their lives. Not much understanding when it comes to larger issues where severe mental health intersect with daily life. And to be honest, it is a hard area to look at. There are no easy solutions and often competing interests and duties of care. But that is exactly the failing of the mental health system. Hard areas are not looked at. They are not dealt with. They are too hard, so they get put aside or pushed onto people often not qualified, but not able to say no, either morally or otherwise."

### **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?**

"Depression seems to get a lot of press and there are easy to reach support for 'garden variety' depression. Whether they work or not, I am not sure. I think homelessness is a major factor. People with Mental Health issues fall into homelessness, often because they cannot live in normal circumstances. But we need to have 0% homelessness as the norm. We need to say we will provide everyone, no matter how difficult their situation with a place that offers a level of stability."

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

"From what I have seen the broken mental health system pushes people to suicide as the only logical thought they may have! As a carer of a daughter who has some pretty severe issues, I can see suicide as a logical conclusion to her situation. She will have a moment of clarity one day that will very logically say 'This is not getting better. I am not ever going to have a quality of life that most take for granted.' "

### **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.**

"As a carer of someone with mental health issues, I would say her inability to navigate simple tasks when unwell is the perfect example of why she cannot be making complex choices about her treatment or paths to take to wellness. As a carer to general hopelessness of the system and absolute failure to provide the right support when needed leads to further mental health issues in a community that has had the great lie of deinstitutionalisation hoisted upon them. Deinstitutionalisation is an easy sell. It sounds wonderful. People with mental health should not be locked up, they should be integrating into the community. Sure, but that shifts all of the responsibility onto the community. When issues are severe there is not the ability within the community to cope. Families break. People break. And worst of all, the people with the issues do

not get the service and help they need."

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

"Lack of services available. Lack of beds. Lack of communication even within hospital departments, let alone between hospitals or services. The justice system is left to take up the slack and it is ill equipped, mostly sad and reluctant to do the job, sometimes completely insensitive to the situation it is dealing with and at best a very blunt and inappropriate instrument."

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

"It is not a one size fits all approach. The needs are complex and deep. These are an army of people who by and large are willing and motivated to help. But they are either left drowning and unable through sheer exhaustion with fighting the system, or often they just give up. You need to talk to families to see what the issues are. Supports are difficult to find out about, all over the place and often beyond the financial means of those looking."

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

"Higher wages surely would help. There are some wonderful people working in the field. I don't think they are motivated by wage alone. But they need to feel like the work they do is absolutely valued, their own need for recovery is met and that they themselves are not just drowning against a rising tide. That is honestly the impression I get from most. They do what they can, but what can you do when things are so messed up. There is no coordination across departments, services, and an absolute disconnect across other sectors than interface with mental health."

**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?**

"From my point of view, with my daughter, I can see none."

**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?**

"This is a massive job that has been left too long. Systemic change, rebuilding and rethinking from the ground up is needed. Innovation and world leading aims should be prioritised. Not massive bureaucracies to support the system. That will stifle change. Empowerment of those that have the energy. Ideally a federalised system working in harmony across sectors (justice, health, education, etc). But if that can't be done then Victoria needs to say 'We will build best in class and guide the rest by our approach.'"

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

"I have so little faith in the system that has done nothing but fail my daughter and our family. It would be an absolute tragedy upon existing tragedies if this commission did not make lasting and meaningful change. I don't think it would be an exaggeration or too far a bow to draw to say a failure to achieve this would directly result in the opposite outcome than is envisaged by this enquiry. That is a heavy cross to bear, but to date I do not see many people willing to bear it and

that is one of the great failings of our system. "

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

"I have attached my daughter's experience, which is our families experience. We need it to be heard. We, like so many others, are desperate. I do not want our details published. But I want the public to understand and for everyone to hang their heads in shame, or rather be angered into change. I am happy to talk further about our experience. But unless it would really make a difference, I need to respect the privacy of my daughter, the feelings of my son should details identify him, and the feelings of my wife. I would want their permission before our story were released with identifying details."

## ■■■■ Story

I have told this story a few times now and do not know any other way than laying out our entire lived experience. I don't know why I find it difficult to distil into short concise bites. Perhaps I am hoping someone will see something we have missed along the way and it will lead to some hope. Perhaps I want to more clearly see the wrong turns, so others can not follow the same map. I think it is maybe trying to make sense of a long and complex set of circumstances that keep leading to a situation of 'negative choices'; that is, no matter which choice you take, the outcome is horrible, and that takes away hope quicker than anything I have ever experienced.

An often repeated explanation is that the system has 'cracks' and that people will fall through them. I don't know if ■■■■ is just unlucky to continually step on those cracks, or if the cracks are so wide that you cannot avoid them. The more time passes, the more I am convinced it is the latter.

This then is the story of the cracks. They are the cracks that people get pushed into when they don't seem to be an easy fit in the existing spaces. They are a dark place with little or no hope.

I will try to keep to the facts and leave emotion aside. It is difficult, but I hope they speak for themselves.

## Baby to Grade 5

■■■■ was born in Japan. I met her mother there and began a relationship with her when ■■■■ was 2. Often look back on that time for markers of ■■■■ illness. My wife in particular is focused on this. Being the first child, I find it difficult to know what is within 'normal limits' and what is not. There was a period of adjustment when I entered her life, night crying and the like, but generally ■■■■ was a happy little kid who liked all things cute young Japanese kids like.

We moved to Australia when ■■■■ was in pre-school. It was the first of the 'cracks' to appear. ■■■■ development at school was not quite in line with most kids. It was not extremely far behind, but by grade 3 it was enough that we got her tested at school (she attended a Japanese English bilingual school in ■■■■) the result was 'it could be an English as a second language thing, it might be developmental'. The speech pathologist or whoever did the testing said it was tough to tell at that stage, but that ■■■■ was a great socialiser, very friendly and popular, so there was that to be thankful for. This was the first crack ■■■■ fell into. She was not bad enough to get help or funding, but she was not quite right either. It's a small crack, but it seems it is possible to fall into one after another, and they add up.

## Grade 5 to 8

We moved suburbs, buying a house in ■■■■, north of Melbourne's CBD. ■■■■ younger brother ■■■■ had been born and would attend all of his schooling in ■■■■. Another social kid, no developmental issues. The differences were marked and in many ways ■■■■ deficits showed more to us. She still lagged at school and we funded a speech pathologist ourselves to help ■■■■ keep up. Still, she was not markedly far behind, and only lagged in English, Maths, and a couple of essay type subjects. She excelled in Art and Music.

At some point during grade 5 we noticed ■■■■ developing what I would describe as common garden variety OCD. She would wash her hands a bit long and would be overly worried about straightening the sheets on her bed. Looking back I would almost laugh at how inconsequential the rituals were. If the definition of how chronic OCD is, is led by how much it affects your life, then this was a negative rating. Looking back. But being concerned parents and somewhat frustrated by her repetitions we found a local psychologist and took ■■■■ along, initially using the mental health plan via our GP and later funding visits ourselves when the plan ran out.

█████ had difficulty grasping some of the concepts from the psychologist, so we found it better for my wife and I to go along, learn the CBT techniques and then teach them to █████ at home.

It was not easy, but it worked. Slowly █████ OCD traits faded. She beat them so that by the time she was in grade 7, there were no traits evident.

Somewhere along the way we took █████ to the LaTrobe Uni free clinical psych testing, recommended by the local psychologist as an affordable way of working out why █████ may have had difficulty following longer instructions, why her language ability was slightly delayed and the like. Their outcome was basically that █████ was slightly delayed, slightly lower IQ, but she would continue to develop, albeit slightly behind her peers, and probably eventually catch up. Again, there was another crack that █████ fell in. They advised she was not bad enough in her delay to afford extra funding or help at school. We tried to compensate by paying for further speech pathology and a specialist tutor in our area.

I recall clearly at the end of grade 7 asking █████ about moving into the next year. Did she want us to speak to the school and organise a slightly revised curriculum. She answered 'No Dad. I don't want to stand out. I got through this year OK.' It was true, she had got through. She didn't break academic records, she still struggled with maths and in a few other areas, but she made it.

### Grade 8 to now

At the beginning of Grade it was a hot summer. I recall there was a Thursday in the high 30's. █████ was in bed. She had a fever. She was covered in blankets and a doona. We kept her off school a couple of days. By the Saturday █████ started talking about strange thoughts. Thoughts of her turning into Michael Jackson. We kept reassuring her, but the thoughts were persistent. She spoke also about seeing my wife's face change in front of her eyes. My wife recalls a particular odour from █████ We have always felt this is important, but am not sure why and no one else has thought so. I have subsequently read that sickness does actually have a unique odour — that of the overactive immune system. And other humans can actually smell when someone is fighting off an infection. This may be another crack █████ fell into. We did not have this knowledge. Would we be in a different situation if we did and if we insisted on appropriate checks?

We booked the local psychologist who had helped with █████ OCD for the Monday. She and we thought perhaps laying around in bed gave █████ too much time to think and her imagination was over active. Get her back to school, among her friends and she would have her mind occupied.

Tuesday █████ went to school. They had a swimming carnival. Toward the end of the school day my wife received a call from the school. █████ had collapsed at an assembly at the end of the day. She was babbling about turning into Michael Jackson and other very strange things. An ambulance was called. █████ was taken to the █████ Hospital.

This was the beginning of years and years of a reoccurring nightmare that has become █████ life. Despite best efforts, █████ did not make it back to school for any great length of time. She essentially has completed school up to grade 7. That used to freak me out. What chance does she have in the job market if she has only been educated to grade 7? That was my worry. Now it is so far down the list of worries that it is not important. Now I internally ask, what chance does she have of being happy and having *any* sort of fulfilling life? Your measuring sticks change.

At the █████ hospital the CAMHS outpatient unit, the psychiatrist listened to our telling of recent events. She quickly said that she suspected a viral infection. If not, it is a mental health issue. An MRI was organised. The MRI, we were told came back clear. This is a sore point for us. One of the many that would build up over the years. My wife seethes with anger when she

thinks of this initial MRI and what we would later learn they missed. One of the many failings for [REDACTED]

We got moved on to another psychiatrist at CAMHS. I recall her telling us that if this was schizophrenia were in for a difficult year. I remember desperately hoping it was not schizophrenia. I would take that diagnosis now in a heartbeat! 1 difficult year. A walk in the park.

Thus began a long series of admissions for [REDACTED] into the CAMHS inpatient unit at the [REDACTED]. I remember [REDACTED] first admission. We walked her around like we were checking out a new dorm. The nurse was relating that 'It is nothing like we see in the movies.' I remember thinking this is the oldest building on the [REDACTED] grounds and looks *exactly* like it is out of One Flew Out Over The Cuckoos Nest. They showed us [REDACTED] room. Scrawled on one wall in giant crazy crayon letters was the word 'DIE!'. It was just scrawly enough that I passed it off to [REDACTED] as 'DIET' and that the previous person must have been looking after their weight. The staff kindly offered to have someone clean it off. Bit late, but hey, they're busy. At least [REDACTED] was somewhere she would get help. We should be grateful.

[REDACTED] went in and out of that unit several times a year, often several times a month. She would be given new meds to try to stabilise her and things would go OK for a while, but things would crash hard again. At home she was catatonic, or destructive. She would kick down doors to get into a room when we tried to move to another room to give everyone space. She opened the door of the car going along the highway when she was not able to get a \$5 jumper she wanted from Savers. Sometime her requests for things were not even possible. She would kick holes in walls. Sometimes there were not even request. There is still a dent in the plaster at home from where [REDACTED] sat bashing her head against the wall. We could not calm her. We could not distract her. We could not assuage her. We could not do anything that seemed to help. We bought all of the sensory toys she seemed to like. We tried all of the therapy advice, the CBT, the exposure therapy, everything the professionals recommended. It did not work.

[REDACTED] took Abilify, Risperidone, Seroquel, you name it she has been on it. Some did nothing. Some seemed to make things worse. At one stage they were considering shock therapy. And we were desperate for help so would have tried it if we thought it would work.

[REDACTED] has been diagnosed with almost every mental condition in the DMV. OCD, schizophrenia, ODD, Autism, Bi-Polar, GAD, anorexia, you name it.

[REDACTED] has cut up her face so blood was streaming down, then ran up the street knocking on neighbours doors. She has tried hanging herself. She has cut her wrists. She has jumped off the balcony (cracked spine). She has thrown large objects around the house. She has kept the whole house up all night screaming. You simply cannot function in the environment we were subject to, but increasingly we were asked to.

We would call the CAMHS unit and their advice slowly turned from bringing [REDACTED] in for an admission to avoiding an admission altogether. We are still not entirely sure why. I recall thinking very clearly at one meeting, they have stopped trying to treat [REDACTED] behaviour, and switched to how we react to that behaviour. It was like they were trying to socialise us to treat it as 'normal' and not look for outside help to deal with it. Fine, but it was far from normal and when it is so extreme, how could we be expected to cope? I remember one time my wife in tears talking to the unit while [REDACTED] was verbally harassing her over something, for days on end, night after sleepless night. [REDACTED] was screaming in the background. My wife raised her voice to [REDACTED] begging her to stop, and the nurse in the unit virtually accused her of making the situation worse. But we have been saying this is not a normal situation, [REDACTED] needs an admission, she is not well. The answer was that [REDACTED] would not get an admission. There were no beds, or an admission was only institutionalising [REDACTED] so was not good for her. So how were we to cope, with a young son also living at home and our own mental health seriously frayed by looking after [REDACTED] If she is dangerous call the police was the response.

Oh we called the police and the police came until they got sick of coming. We would have the paddy wagon at our house, sometime with an ambulance, sometimes without, at least once a

week, often 2 or 3 times. The police would say that it was not a police issue, it was a mental health issue. We would agree, but point out that the hospital had refused [REDACTED] and told us to call the police if [REDACTED] was being dangerous to herself or us. They would drive her off to hospital, she would be assessed and either admitted or not. More often not. This always left us stunned that someone so at risk could be pushed back home.

This went on. For . Years.

I have only touched the surface of what went on at home. The damage emotionally, physically, financially, in every way imaginable. [REDACTED] was ill. She suffered. My wife, my son and I were all pulled in by her illness' gravity.

But she is our daughter. We can't give up on her. Clearly treatments are not working. We research everything we can. We come across an illness known as Paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). It basically says some kids get an infection, like a virus, where the autoimmune system kicks into overdrive and antibodies that would normally attack a virus cross the blood brain barrier and attack the brain, causing inflammation. Symptoms match exactly [REDACTED]. It is not widely accepted, but nor is it voodoo science (believe me we had already tried holistic medicine, homeopathy, mediation, you name it).

Treatments for PANDAS include blood transfusions (to get the right antibodies in there), or a course of antibiotics, to fight the infection. We raise it with the [REDACTED]. We were not met with enthusiasm. They would not prescribe antibiotics. We were dumbfounded. Sure, it might not be gold standard, but nothing else was working, why wouldn't you try a course of antibiotics? They talked about shock therapy. What was the risk from antibiotics. No. We pushed and pushed and felt ridiculed and ignored. We could not reconcile the logic of the situation. [REDACTED] had several different diagnosis. Her medicines were changed routinely in an attempt to get things right. Things were not working. Surely they could see we were motivated parents, keen to find a solution to [REDACTED] issues and logic dictates that a few antibiotics were a small risk to try, even if studies into PANDAS were ongoing and inconclusive. We engaged a US neurologist. It was expensive, but he treated PANDAS in the US. We could not afford to go to the US, but he liaised with the hospital for us. They listened. They would not prescribe antibiotics.

We went to a local GP. After 10 minutes describing our situation he got it. OK, it is not gold standard, but there is some logic to it and what's the harm. He got it. As parents, we had to try everything we could to make our daughter well. No one else seemed to be willing to take the lead and say 'This is not working. We need to try something different.' This is one of the biggest failings for me. I always thought in a chronic health situation like this *someone* in a professional role, in a health sector role, would take charge and say 'This isn't working. We need to look further and creatively and I know just the health professional to lead it, because they are educated and knowledgeable and know which rabbit holes to go down and which ones are just selling false hope.' But no one does. It is all on the carers to advocate for people that cannot advocate for themselves.

So we gave [REDACTED] antibiotics (when she was out of hospital, because they would not give them anything not prescribed by them when in). Like the meds, things improved for a while, then they fell off the cliff again. I don't know if this is the type of antibiotics, or it just wasn't what [REDACTED] problem was. I have read confusing accounts of different antibiotics having different efficacy, but I am not an expert. And nor could I afford to engage the expert. I didn't even know if it was right. We were also privately engaging an OCD specialist, trying to talk through some of the issues we were facing with the hospital, the idea of this new illness and so on. But all the while, we had the immediate issue of dealing with [REDACTED] behaviours, when the hospital kept pushing her out of the inpatient setting. I get it, but why is home more suitable, when someone is out of control?

My work naturally suffered. Our relationship suffered. Our son's well being was a constant worry. [REDACTED] immediate well being and future was the first and last thing we thought about every day.

In desperation my wife decided to take [REDACTED] to Japan to see if their health system could do what ours could not.

[REDACTED] was placed in a mental health facility in Japan for 3 months. It is not a happy time for her. The nurses are quite strict and process must be followed, and that did not sit well with [REDACTED]. My wife stayed in Japan, away from our son and her life here to help [REDACTED] and to give our son a break and allow me to regain some sanity. She is an absolute hero.

We did get [REDACTED] in to Kyushu University Hospital. It is the top hospital in Fukuoka city. They did full testing, neurological and psychological. They did within a couple of days tests we had been advocating for well over a year at the [REDACTED]. Blood work, MRI, spinal fluid testing, a full psych evaluation and so on. We had never seen this cross communication and effort between departments at the [REDACTED]. They seem to operate separately and independently in Australia and this remains our experience in spite of [REDACTED] moving hospitals here in Melbourne. In fact, we had to give [REDACTED] ([REDACTED] current hospital) [REDACTED] medical history. We had to ask if they had chased the [REDACTED] for it, or if the [REDACTED] had sent it. Surely this is basic!

An MRI examined by the neurologist at Kyudai showed white spots on [REDACTED] brain. It was the neurologist's opinion that [REDACTED] had brain damage of some type. He had heard of PANDAS. In fact, his reaction when we raised it was in stark contrast to the [REDACTED]. He wanted to see. He wanted to explore. It was a view formed by professional curiosity and a willingness to get to the bottom of what was going on. It was not a blank stare and a rejection of anything outside of the norm.

The Japanese neurologist concluded that PANDAS was an issue with [REDACTED]. He was of the opinion that [REDACTED] had acute disseminated encephalomyelitis (ADEM). This is characterized by a brief but widespread attack of inflammation in the brain and spinal cord that damages myelin sheathes in the brain. It is the precursor to MS. Get it once, it is ADEM, multiple times, MS.

He was further of the opinion that [REDACTED] had some underlying psychiatric issues. What he could not say for sure was the exact mix of the two. He was confident, however, that [REDACTED] issues would not have been as severe without the brain damage.

I went to Japan to accompany [REDACTED] and my wife home. Our last night there, the police were called by us. We seemed to be getting to the bottom of [REDACTED] issues, but practically nothing had changed.

Back in Melbourne we go to the [REDACTED] with our findings. We felt dismissed still, but our voices were insistent. It is a horrible feeling to be fighting against the hospital for thorough help and assistance. You should feel like one team, but we did not. We got the [REDACTED] to dig out [REDACTED] original MRI, from her first admission back at the beginning of Grade 8. It showed exactly the same white spots as the MRI in Japan. The psychiatrist we were dealing with at the time (when [REDACTED] was an outpatient - different to when she was an inpatient) apologised for them not picking up the white spots. My wife takes this as an admission of fault by the hospital. I am not sure that person was not trying to be sympathetic. It has never been explained to us clearly what missing the initial MRI result meant. We were set up with an appointment with a neurologist at the [REDACTED] (which we almost could not go to due to [REDACTED] worsening behaviour) but that neurologist said they white spots had no bearing on [REDACTED] behaviour and the location of them would not explain her behaviours. The doctor said that everyone probably has white spots on their brain.

My wife called the Japanese neurologist and relayed that finding. He was stunned. He could not believe the [REDACTED] neurologist could come to that conclusion given the sudden and rapid onset of [REDACTED] psychosis and the severity. He was of the opinion that there are further spots on [REDACTED] brain that an MRI simply is not capable of showing, and this is from his long experience in the field (this is a man who is the top neurosurgeon in the top hospital in Fukuoka, trained and worked in the US, not some 3rd world Asian doctor as some made us feel). He further offered the opinion that the [REDACTED] neurologist sounded like he simply was not interested in exploring the possibility of [REDACTED] issues being neurological.



We wonder what the ██████ said to the ██████ in the referral process. Was there mention of MRI issues showing up but not being picked up on? We have this nagging feeling of a stitch up, covering professionals against an angry and desperate family. But then we move into the realms of conjecture and conspiracy. I am not sure if there isn't just incompetence and a lack of logical thought all round.

In the meantime ██████ behaviours continue to take a toll on our lives. She is not improving and the hospital seem more and more reluctant to treat her in any inpatient setting. The police are called with regularity, as there is no other choice. They are sympathetic usually, but it depends on the officer.

One time a couple of police are called after a particularly harrowing day/night. ██████ had spent the day insisting her younger brother give her a hug. He does not want to. We do not want to force him. He is traumatised already. He is scared. It seems like a simple thing, but part of the advice from the hospital is not to give in to ██████ demands. She needs boundaries and they must be held fast. In any case, you could give in and the fixation would switch to something else. ██████ goes on and on and on, hour after hour after hour. She goes into his room and flips his bed upside down. We have tried the hospital. No help there. We call the police. The police turn up and ██████ sitting on the floor crying. She looks small and meek. I get it. The policeman comes in, asks what the issue is. He decides that for god's sake, just give her a hug and it is all over. We try to explain that this is not the answer. He tells us it is. We argue and try to explain our situation. The hospital will not assist, they tell us to call the police. ██████ will not stop whatever she is fixated on. The latest diagnosis is autism, among other mental health issues. An intervention order has been suggested. Please, what can we do? He gets pretty angry at us for calling the police for this issue and dealing with things this way. They leave and we feel completely unsupported with no where to go.

The next day we go to the ██████ police station. We ask to speak to the Sargent in charge. She comes out. I explain our situation. They musty know us, the police have been to our house weekly. We beg her, please tell us what we can do to make things easier for them. We do not want to call them, but we are getting turned away from hospital and told to call the police. She says she has an autistic child and that this is not the way to deal with them. We try to explain it is perhaps more complicated and complex than that. A sit down discussion with the ██████ police, ██████ outpatient care team, etc is suggested by the Sargent. We readily agree and thank her for her time. Perhaps we can come up with a better plan in time of emergency.

We do not get a sit down with the ██████ police. We get a notice of an intervention order, taken out by the ██████ police against my wife and I, not to do anything to harm our daughter. Basically us calling the police on her is harming her. The officer that hands me the order when I go to the ██████ station to pick up the notice essentially tells me he cannot believe they are taking this approach. I take it in silence. The message is clear to me. Do not call the police. They are not dealing with this any longer. That avenue of support, faulty though it is, is closed to us. I get it, the police are not the right function for mental health issues. But the hospital are not taking responsibility. The police drop the charge before we get to court, but not before we spend countless weeks worried about what this means for us, lawyers fees and sleepless nights to add onto our already sleepless nights. I cannot drive past the ██████ police station without reliving that feeling of being punched in the guts.

My job is hanging by a thread. Our finances are in debt. Our family unit is not functioning.

We arrive at the first great decision of negative choices. A decision where no option results in a good outcome. We had explored respite care for ██████. It was almost impossible to get and behaviours would continue once ██████ was back. Stress levels all around spiked straight back up. We kept asking the hospital what options were for housing for ██████ and nothing was forthcoming. We reached out to government departments, mental health organisations, everywhere, no one could tell us any avenues of help. ██████ must have been 16. We were told the options when she was an adult were much better, but we did not think we, or possibly ██████ would survive another 2 years.

I had asked the DHS for help and nothing eventuated. We made the absolutely heart breaking decision to take [REDACTED] to the [REDACTED] for ED evaluation, then to inform them that we were not taking [REDACTED] home. It had been made clear to us that the only way to get the DHS involved was to abandon our daughter. I cannot stress enough the guilt and utter disbelief we felt (still feel) at this decision. Do we keep [REDACTED] at home at dire risk to herself and our son, or do we throw [REDACTED] to the wolves in DHS housing, where she is exposed to kids who themselves have deep seated issues.

We live with that drive home from the hospital every day and will never forgive ourselves for having to make a choice in which there was no choice.

The DHS were actually pretty good once they were forced to step in. We were investigated, but to their credit they could see it was not a situation they might normally deal with. They actually apologised that we had been left for so long to deal with the issue and that we had been forced to do what we had to do.

We were desperate to avoid homelessness for [REDACTED]. The first unit [REDACTED] went into she was sexually assaulted. She had property stolen. The second home she went into she was housed with another kid who seemed to have deep-seated mental health issues. They formed a bond and there was a bit of stability. We kept contact and visited [REDACTED] weekly and had her home when she was well and stable.

When [REDACTED] was turning 18 accommodation was organised. The first did not work and an incident in the initial accommodation brought memories of her sexual assault, so [REDACTED] was moved to [REDACTED], to a mental health care unit. It was great for a while. It was not 24 hours, but during the day it was supported, and it was close to home. At one stage [REDACTED] was pretty stable, looking at further schooling and the future. She even had a conversation with me where she said if she had of stayed at home, someone would have died. It didn't change my guilt.

The units were mixed sex and [REDACTED] fell into a relationship with a boy there. His mental health issues became [REDACTED]. Insomnia and depression mainly. There was a couple of girls in the unit next to [REDACTED] that liked to go out. She later admitted to going out with them and taking drugs. This has later surfaced in [REDACTED] psychotic talk and used as a potential reason for her behaviour. I believe this is one off type behaviour and after this time [REDACTED] has not been taking drugs, but it has been used as an excuse to not treat her mental health. Oh, this is a drugs issue. Overall, [REDACTED] dealt with this situation at [REDACTED] maturely. She stopped the relationship with the young man, even though it hurt her emotionally (as she was in love, but could see the negative effects), and she stopped going out with the girls.

The unit had a time limit (2 years maybe) on occupancy. It was a real shame, because [REDACTED] was doing well and we could see improvement. But hey, again, that is the system, just another chance to worry about what next for [REDACTED]. As she was doing well within the organisation (Mind Australia), she was transferred to another unit of theirs in [REDACTED]. This seemed even better, it was staffed 24 hours!

But the move was unsettling for [REDACTED] and her behaviour slowly changed for the worse. We could see it coming a mile off. We had seen it so many times before. As she was in a different catchment area, she was being seen by a different hospital, [REDACTED]. We kept saying to her hospital liaison, she is getting worse and this will not end well. Her careers kept saying the same ting. [REDACTED] herself kept wandering out at night, turning up at police stations, or emergency departments, babbling crazy things. If that is not a direct cry for help, I do not know what is. But again, she would be sent back to her accommodation.

Our biggest fear was that [REDACTED] behaviour would cause a crisis in her accommodation. She always felt one small step from homelessness. It was a constant conversation at home 'What if they kick her out, or simply can't control her? Where does she go then?' We knew how hard it was when she was unwell.