

A short history:

When my daughter started showing symptoms of mental health issues, I took her to several counsellors. When my daughter found one that she could talk to at [REDACTED] she was told that she 'didn't have to come back if she didn't want to'. My daughter, who was happily making another appointment, decided not to come back. She was 13 years old.

Subsequently, at age 14, my daughter was clearly suffering from anorexia. Her weight was very low and she was restricting food intake to almost nothing. The GP referred her to [REDACTED] but there was a wait of 4 weeks to get in. I did call and ask to get in earlier when my daughter's weight was extremely low and she was unable to stand without support but they said if she was still drinking water she would have to wait.

Ultimately I took her to [REDACTED] Hospital emergency department. Although she had ketones on her breath and in her blood, the doctors sent us home and said that they would call mental health services and get them to follow up the next day. An appointment with a pediatrician was arranged by mental health services and my daughter was sent straight out to the hospital by that doctor. This was when my daughter first had contact with mental health services.

Over the following 18 months, my daughter spent a lot of time in hospital, either to be refed, or as a result of self-harm including cutting herself and overdoses of prescription medication. She was admitted to the hospital 31 times in this period.

Despite all this, the local mental health team were unable to provide my daughter with a psychologist. They said that her BMI was too low and that it would be a waste of time. They also said that they had no-one to fill that important role. Appointments were made with 'case managers' which were very often cancelled due to ill health or people going on leave. The 'team' talked a lot, didn't say much, and seemed to be out of their depth altogether but were unwilling to let my daughter be a patient at [REDACTED] despite the fact that we were willing to support that.

Over the following years my daughter has been in and out of hospital, both medical and psych. She has had workers who have sworn at her and discussed inappropriate things with her, she has been placed into inappropriate accommodation, workers who don't show up ever because they are sick, assessments made and not followed up on, things promised and then withdrawn.

My daughter has self-medicated to ease her distress. She now has very complex mental health issues, potential brain damage (neuro-psych assessment recommended 2 years ago but still not organised) and drug dependence issues.

Now, in 2019, my daughter still does not have a psychologist (she has had one but he has moved on and she has not been given a new one). I'm not even sure if she has a case manager or a treatment team at all, she lives at home with us and she sees one mental health worker sometimes. Last year I made a complaint to the [REDACTED] to see if something could be done. I was told that things were happening. I have yet to see any evidence of this.

My feeling is that our family has been let down by the system and that my daughter has suffered neglect and abuse at the hands of the system. I have been proactive in trying to get help for my daughter but they come on strong and then fizzle out altogether.

This story is too big for me to tell succinctly, besides the fact that after 10 years I am still overwhelmed by the situation.

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

## Supporting Document for Individual Formal Submission to the Royal Commission into Victoria's Mental Health System

When my daughter was 13 years of age I took her to several counsellors after she started showing symptoms of mental health issues. She found one she could speak to at [REDACTED] but at the end of the appointment she was told "you don't have to come back if you don't want to". With this, my 13 year old who was in the process of making her next appointment decided not to come back.

She is 24 years of age now, with diagnoses of Anorexia Nervosa, Borderline Personality Disorder (BPD) and substance dependence issues (AOD) that have progressed from over the counter medications to heroin. Some clinicians have also diagnosed her with complex PTSD and OCD traits. I have been caring for my daughter for the past 10 years.

**My daughter has spent a lot of time in hospitals, either to be refed, or as result of self-harm including self-mutilation and overdoses on prescription medication.**

**By 2009, when she was just 15 years old, she'd had so many hospital admissions I had to stop counting. Over this 18 month period she was admitted to hospital 31 times.**

She has self-harmed and overdosed so many times and often absconds from services. Every time she runs away I worry what she's going to do. My daughter has just about been in every hospital in the Gippsland area and Melbourne. She vacillates between wanting me involved in her treatment and care and not wanting me involved at all, just as the mental health system does.

We have tried to access every support possible over these past 10 years, yet she has not been supported to recover or even get the bare minimum of treatment. As such, my daughter has become more unwell and has self-medicated to ease her distress. The stress of navigating the system and dealing with her highs and lows has impacted me, as her mother and carer, greatly.

**Time and time again, I have been sucked in by services to be involved. Then they spit me out when I demand too much for my daughter, complain too much or when they think they've got it under control. But all of a sudden when it is too hard for them, they throw her back to me without support.** Currently, my daughter is basically completing a homebased withdrawal and no one has given us any support or advice. As her mother I am expected to be the one to support her, to know what to do. The most recent mental health worker wants me to be more involved. Of course she is my daughter and I want to be able to help, but I am exhausted.

The following outlines our experience with the Victorian mental health system and the key issues that the Royal Commission must address:

### **Unable to access early intervention services:**

When my daughter was 14 her anorexia became very obvious, she was very underweight and had begun restricting her food intake to almost nothing. Her GP referred her to [REDACTED] but there was a 4 week waitlist. I called to get her in earlier as she was so underweight she was unable to stand without support. They told me if she was still drinking water, she would have to wait. My daughter should have received treatment when she needed it, when we asked for it, before waiting for things to get worse.

**Revolving cycle of referrals:**

As my daughter was still severely underweight and without treatment I took her to [REDACTED] Hospital ED. She had ketones in her breath and blood, yet the doctors sent us home with a referral to the mental health services for the following day. The mental health services made an appointment with a paediatrician and as soon as we saw him, he sent my daughter straight back to hospital. We shouldn't have to go around in circles like this when people are in desperate need of treatment.

**Not listening to families and acknowledging concerns:**

As well as the times the severity of my daughter's anorexia was not taken seriously, there have been times when workers ignored my concerns and it almost cost my daughter her life. When she was living in Melbourne she would treat me so badly I cut down on visiting. I called her worker requesting they check in on her, they just thought I was being a nuisance. I had been begging her worker to go and see her for a week but they just ignored me. That same week my daughter called and hung up several times. I knew something was wrong and I called an ambulance for her, the ambulance showed up and saved her from an overdose. The worker should have listened and acted.

The last time I wrote to the [REDACTED] to complain about my daughter's lack of support and inability to appoint a regular psychologist, they contacted me saying "you may not be able to see things happening but they are behind the scenes". There's still nothing happening, she does not see a psychologist, her behaviours and anxiety are getting worse, and she is still suffering from anorexia that is going untreated.

**Treatment of family & carers:**

In the early days I was extremely involved but I got told to butt out and let my 14 year old daughter do things for herself. They told me, just treat it like she has cancer, which did not make any sense because if she had cancer she would never be told she was "too sick for treatment".

Services involve me more than I would like; my life, my career has been taken over.

Her mental health service asked me to do the Family Connections course for families with BPD and I was disgusted with the content. I was hoping to get strategies to support our relationship but it was all about capitulation. I had been hoping it would be an empowering experience but the course was premised on the assumption that carers were always invalidating their family member. When I decided to no longer attend, my daughter's worker told her she was "disappointed in me". Another time when I was unable to take my daughter to an appointment because I was working, her worker said "mum just has to suck it up". It is unfair to blame family or expect us to be available 24/7. We are entitled to our own lives and we are not the ones being paid to provide support. I am aging and won't be about forever.

**Reliance on medications:**

Currently, my daughter is on a home detox to withdraw from benzodiazepines, but it wasn't that long ago that they filled her up with medication. They would just throw more and more medication at her because they didn't know what to do with her and her behaviours were getting so bad. I understand the importance of some medication for some people, but it should not be the only form of treatment. My daughter didn't have any addiction problems before she was put on all these medications and now she is having to withdraw from many of them.

**Issues with dual diagnosis treatment & support:**

As a teenager my daughter was in and out of hospital being refed. Due to her BPD she did not fit well in hospital, however clinicians refused to diagnose her until she was 18. As such, the treatment plans they set were unrealistic and did not take into account her BPD. She has tried attending DBT group based therapy sessions but the methadone and changes to medication have increased her anxiety and left her unable to attend.

My daughter has tried a range of programs to address her substance dependence issues. She has detoxed before in order to get into rehab, but they changed their minds and wouldn't accept her because of her frail state due to her eating disorder. My daughter has now done 3 day-hab's, two of the three times men have followed her home from the service and taken advantage her when she is in a vulnerable state. Staff should be checking in when they see this happening to keep her safe – they have rules about relationships and could have protected my daughter. She has been on the methadone program 3 times now. Despite her complex history, they left her to do it on her own at home with me, without a nurse or AOD counsellor. They are setting her up to fail.

There is constant conflict between the medical side and the mental side, and when you're looking at anorexia and other diagnoses there's no avoiding a combination of both. They need to learn to work together.

**Unreliable and ill-equipped workforce:**

The community mental health service that my daughter was referred to talked a lot, but they didn't say much. Despite the 31 hospital admissions the mental health services were unable to find my daughter a psychologist. We were told her BMI was too low so it would be a waste of time. They then added they had no one available. They were out of their depth with the severity of my daughter's symptoms, but they were unwilling to let her be a patient at ██████ despite us, her family, supporting this. It is not uncommon to have workers not show up, have assessments made but never followed up, and things promised but then withdrawn. One worker told us she had 130 people on her caseload. A neuro-psych assessment was recommended two years ago as my daughter may have brain damage, but this assessment has still not been organised. The 'support' team personnel change regularly which usually means going back to square one and long periods where no contact or support occurs.

**Inappropriate workforce:**

Across medical and psychiatric hospital admissions and AOD services, my daughter has had workers who have sworn at her, who discuss inappropriate things with her and who placed her in extremely inappropriate accommodation that exacerbated her drug dependence. At one stage she had a hospital paediatrician, who treated her really punitively during her recovery. She put her into ██████ inpatient unit and made her earn the right to have access to basic outlets like watching TV by getting her to ignore her symptoms and pretend like she didn't have mental health issues.

**Failings of the NDIS:**

The NDIS was supposed to bring support and coordination to my daughter's care, but she has been on it a year with hardly a cent spent because her support coordinator has not organised anything. They have held care teams without me invited or at times when I am unable to attend, despite my daughter requesting that I be there. There have been times where care team meetings have been cancelled and never rescheduled, because the support coordinator felt it wasn't imperative, despite there being none of the supposed supports in place.

**To the Royal Commission, I want to see changes in our system so that my daughter can be supported and I am no longer expected to do it all.**

We need a holistic approach to treating eating disorders and other mental illnesses.

We need to address symptoms early before they get so unwell they cannot work on recovering themselves. To do this we need funding in regional areas too, ensuring that everyone has access to the services they need.

Many often speak of early intervention, but this model needs revision. Forcing someone into hospital and forcing food into them does not improve their relationship with food or their mindset.

There is constant conflict between the medical side and the mental health side of treatment and recovery. When dealing with anorexia there's no avoiding a combination of both. These sectors need to work together.

We need flexible and tailored intervention to suit the individual's needs and the complexity of their issues, so they are not continually pushed and pulled through the mental health, AOD and other systems without receiving effective treatment.

Families need to be valued and supported. There used to be funding for carer support workers, for education, for trips away where you could learn as well as meet other people with shared experiences of caring. We need these programs back so families can get information and feel respected.

Families deserve to be acknowledged for the fact that we know our child better than most services will. We deserve to access to clear information and be able to have frank conversations with service providers about what is actually happening and what we as carers can do to support.

We also need accessible supports for siblings, as care and attention often goes to the unwell child. Siblings need support too.

**My daughter is still without a psychologist, she is very unwell and is at home with me going through detox and withdrawal alone, awaiting a place in independent accommodation. I am aging and won't be about forever.**

Sometimes I wish she could put herself out of her misery because I understand that she is in so much pain, but she's still here fighting it.

**It is time the system changed to support her and allow her to keep fighting.**

**From:** [REDACTED]  
**Sent:** Monday, 9 July 2018 4:36 PM  
**To:** [REDACTED]  
**Cc:** [REDACTED]  
**Subject:** RE: Desperate for answers please

Dear [REDACTED]

[REDACTED] has just been discharged after a night in hospital after yet another suicide attempt, cry for help, attention seeking act, or however you might perceive it, this time though she was found with a slip knot around her neck and over her door and it was lucky we found her.

Physically she is just OK but mentally she is not, and has been struggling very hard for the last year, without much support from the services who say they care.

A brief explanation of her complex condition:

What [REDACTED] endures each day. Obsessive Compulsive Disorder, Borderline Personality Disorder, PTSD, Cannabis addiction, Valium addiction, recovering alcoholic, Heroin addiction/methadone withdrawals, acute anxiety, low self-esteem, suicidal, self-loathing, socially isolated by her anxiety, and an inability to make informed, sensible decisions due to missing secondary school while in and out of hospital for refeeding through her eating disorders of Anorexia and Bulimia for 11 years. A very complex and heavy burden.

She is reducing her methadone and Seroquel medications without any guidance or support from an AOD counselor or withdrawal nurse. She doesn't seem to be managing this well as she is particularly extremely volatile in mood and behavior. She is encouraged to continue to smoke cannabis, but this costs most of [REDACTED] pension, is difficult to procure, and so causes [REDACTED] increased stress and anxiety. I must add that [REDACTED] has just commenced attending a Day Rehabilitation program. Her third time through, although last time she didn't finish as an older male participant used her for sex and spat her out, leaving [REDACTED] being vilified for having him lose his place in the program even though it wasn't his only indiscretion. I think having [REDACTED] do this program allows the support services to believe that they are supporting her even though most of her issues are not being addressed at all.

Her eating disorder continues, and as far as I can see isn't being addressed by anyone. Her psychologist has left and is yet to be replaced and even he was on leave for a long period recently. Her treating team seem to be happy for her to exist on the cusp of hospitalisation for her weight – 40kg without having any knowledge of the of truth of her dietary habits. Apparently the gastroenterologist has advised her to follow a FODMAP diet which restricts even more. All this without reference to anyone or anything.

Even though she is not considered to be well enough to have a stay at PARCS in [REDACTED] her Lifestyle worker (or whatever he is) has her on a waiting list for independent public housing in Melbourne. Go figure. While I am well aware that living at our home is not a positive situation for any of us, there must be a supported option. Even living independently locally would be a much better option in my view. [REDACTED] says she wants to live in Melbourne on her own and the system says that should be facilitated even though it is clear that independent healthy living doesn't seem like a real option for her unfortunately.

It would be great if the people who work with [REDACTED] could start bothering to have some insight into the truth of [REDACTED] illnesses and situation. They accept what she says at face value. They tell me on one hand that her decision making capacity is impaired, that her mental illness causes her to be reluctant to engage but on the other hand tell me that she is an adult who can make her own decisions. Every decision [REDACTED] agonises over or makes has an impact on my life. I know I have and will be told that I have a choice and should just kick her out, however I find that attitude unhelpful. When she was first ill at age 13 they told me to treat the situation as though she had cancer. I'm not sure how that would be, however I do know that she would have received treatment and heaps of support if she had cancer. I have stepped back heaps and no longer enable as I know I once did. Imagine what they would say if she did have cancer and I kicked her out of home.

I don't know how much more I have to give to the situation anyway. Her volatility and abusive behavior has us in a state of constant stress, concerned about our own state of being as well as hers. Our lives are largely on hold while she is living in our house. – at the moment I must say that my plea for help and answers is motivated by sheer desperation rather than a cry for justice.

Mr [REDACTED] is it possible that the [REDACTED] really truly review this case? Just asking the providers for information does not ensure an accurate or relevant reflection of the situation.

I feel that she needs a thorough physical and mental health assessment including the neuro psych assessment recommended by the last psychiatrist she saw for which there is no funding apparently.

I hope I receive a response to this email.

[REDACTED]

**From:** [REDACTED]

**Sent:** Sunday, July 1, 2018 10:53 PM

**To:** [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

**Cc:** [REDACTED]

**Subject:** Desperate for answers please

Dear [REDACTED]

I am writing to you because I am at my wits end and do not know where to turn to for help.

I don't really know how to tell the story, as to say that for the last 9 years we have had to deal with not only the illness, but the system that is supposed to help us, is not sufficient. Yet to go into all the ins and outs would take forever and I am not up to the task in any case.

Briefly though, my daughter, [REDACTED], has been ill since 2009 when she was diagnosed with anorexia and suspected borderline personality disorder. She was treated initially by

██████████ Community Mental Health services, ██████████ Hospital pediatric services and also ██████████ at ██████████ She has been treated at the ██████████ Hospital among others. She has been on a cocktail of benzodiazepines, anti-depressants and anti-psychotics since she was 14 year old. She has taken multiple overdoses over the last 9 years. She has been placed in inappropriate housing without support. She has had a heroin habit and is reliant on cannabis (and is encouraged to keep using cannabis by health professionals who don't pay for it or provide an affordable or reliable source.) Her workers have been inconsistent, or on extended leave, or discuss their private situations in far too much depth, or sick, or on holiday or powerless.

In the past year ██████████ has been denied residential rehab because she is not well enough. She has been discharged by CMHS for no reason, her MIND worker has been sick and not available, her psychologist, AOD worker and care team leader have all been away for weeks at a time. She has had a referral accepted by MACNI but that seems to have gone up in smoke. There is no idea, no plan, no action and no improvement.

██████████ has been assessed by a psychiatrist for a diagnosis and medication review at the request of her care team leader. He recommended a neuro-psych assessment but it seems that there is no money anywhere for this. It was supposed to go into her NDIS plan but wasn't included. The NDIS planning debacle is yet another story.

Currently ██████████ is living at home. She is not travelling well and has the insight at the moment to see that she needs some care. She is still taking prescribed medications including methadone which she is almost off. The situation is not tenable for any of us. There is a suspicion that the cocktail of medications commenced at such a young age has impaired ██████████ capacity to manage. Her moods are volatile and she is abusive, she is isolated and depressed and feels suicidal a lot of the time.

Two weeks ago ██████████ asked to be admitted to PARCS in ██████████ for some respite and a chance to stabilise with some professional support but has been advised that she is too sick for that. She cannot go to the psych unit at ██████████ Hospital as she is not sick enough. ██████████ has expressed that she feels that they have told her to go and die somewhere else. And while she is too sick (chronically) to live in a supported environment for a month they have her on a wait list for independent public housing in Melbourne – doesn't make any sense to me.

██████████ has a complex set of issues. We have been told for years that the part of ██████████ that is reluctant to engage is part of her mental illness, and yet if she doesn't show sufficient enthusiasm she is ignored. Even when she does engage she is ignored.

I really don't know what to do or where to turn. I am exhausted and have been for a long time. Please help us find some sense and solutions.

██████████

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**Online complaint form**

() to: help

27/04/2017 05:53 PM

Below is the result of your feedback form. It was submitted by  
() on Thursday, April 27, 2017 at 17:53:34

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firstname: [REDACTED]

surname: [REDACTED]

myemailorphone: [REDACTED]

fm-altphone: [REDACTED]

besttime: email, any time

fm-interpreter: no

fm-language: English

fm-onbehalf: no

fm-relationship: Mother

fm-firstname2: [REDACTED]

fm-surname2: [REDACTED]

fm-complaint: I have a few complaints but will stick to one at the moment. My daughter [REDACTED] has complex issues and has been suffering from anorexia and BPD for 9 years or so. She also has drug and alcohol issues. 3 weeks ago, on Friday 31 March, [REDACTED] took around [REDACTED] valium tablets in an attempt to end her life. She was admitted to [REDACTED] Hospital. To keep it short, she was sent home in a taxi on Monday April 3rd to a home where there were no supports as we were on our first holiday in 11 years and we had been advised by hospital staff that she would not be discharged until there were supports in place. [REDACTED] had recently been living in QLD and had not been registered with our mental health services again at this stage. After waiting for 3 weeks for a follow up call or visit, I rang today to discover that no referral had been made by the hospital to the mental health services. [REDACTED] has been struggling throughout this time. I have called the hospital to ask for

a follow up referral today but have not heard from them.

fm-service: [REDACTED] Hospital

fm-servicelocation: [REDACTED]

fm-servicecontact: [REDACTED]

Submit: Submit the form

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