

██████ is a mother of 4 primary school aged children, living in Melbourne's north western suburbs. ██████ was working as a legal secretary for about 5 years before going on maternity leave with her fourth child in 2016.

Her youngest child was born 3 months pre-term and needed to spend a lengthy period in the ICU and neo-natal unit of a Melbourne hospital. Witnessing her baby so sick and close to death, she describes as a traumatic experience. She explained that at this time she was struggling to come to terms with how the birth had worked out, why it had worked out this way, along with the practical considerations of how she would care for the rest of her family and visit her child in hospital 45 minutes drive from her home.

The family received support from the medical staff at the hospital and she said she also met a few families who were in/had been in a similar. She said she had tried to access counselling support but that her time, energy and focus were squarely on what had to be done immediately (visiting and caring for her children) that it didn't eventuate. "My key focus was how we were going to cope".

██████ husband was working in warehousing during this time. He was working reduced hours to allow him to drive his wife to visit their daughter, however he 'lost his job' because he could no longer take the time he needed to care for his family.

Whilst her fourth child was in hospital, ██████ oldest daughter experienced the first episode of what was eventually diagnosed as a rare genetic disorder. This disorder causes her daughter to experience a temporary paralysis of her body from the neck down. Her daughter was 9 years old at the time. This condition was and obviously still is a huge concern for ██████ and her husband. She says there is little information and understanding of the condition and accessing supports (such as the NDIS) has been incredibly difficult. The condition has had a significant impact on her daughter's mental health. ██████ said she has gone through periods of being desperate to find more information about her daughter's diagnosis and has trawled the internet for whatever she can find.

██████ initially assisted her daughter to visit a GP for a referral to see a counsellor via the Better Access program. She said they exhausted the allowed number of referrals and could also no longer afford the gap fee. Apart from losing the family's main income, the family's expenses had increased due to the medical needs of the children. ██████ said she had to rely on the school to provide a mental health intervention and apparently she has some access to a school counsellor and psychologist this way.

Nearing the end of ██████ maternity leave, her second daughter was experiencing some developmental difficulties, which lead to her eventually being diagnosed with a number of mental and behavioural disorders related to the autism spectrum. ██████ said her employer was "wonderful" and allowed her 4 extra months on top of her maternity leave and sick leave and other entitlements. By this time her youngest daughter had shown great improvement, however, due to the ongoing needs of her oldest daughters, ██████ decided not to return to work.

Since making the decision to care for her children as a priority, [REDACTED] and her husband also decided to sell the family home to support this decision. They have been renting for a year or so and have recently been given a notice to vacate.

[REDACTED] daughter is now in her final year of primary school and is increasingly showing signs of mental distress, which concerns [REDACTED]. She said this also has a big impact on the family and [REDACTED] own mental health. [REDACTED] mentioned she finds her husband, her family and her friendship network very supportive.

Before her children's diagnoses [REDACTED] said she was very social and enjoyed connecting with others. She said that her experiences and the associated difficulties have made her more introverted. She said the family doesn't go out as much now for reasons related to her children's conditions but also because of financial constraints and other stressors.

As well as her family, [REDACTED] finds support from carer groups, including an online Facebook group for mothers/families of other children with the same condition as her oldest daughter. She said she has made friends through the group. [REDACTED] said she has been offered a respite service through a carer agency she is involved with, including movie tickets for her and her husband to have a night out. She spoke glowingly about this. She said it was the first time she had been out with her husband to the movies in 3 years. The carer agency also gave her tickets for her to take her family on an outing to Healesville Sanctuary, which she says was an amazing experience for them.

[REDACTED] spoke about her drive to care for her children and see them meet their potential. She said she would do anything to help them to be their best. She said she will continue to work hard for them and keep fighting, even when they get knocked down.

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

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Name

[REDACTED]

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

I don't have a suggestion right now but I wish people would stop discriminating.

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?

It is hard to say. Mental health is very difficult to talk about. There will always be someone struggling. It is just the way the world is.

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

More support in the way of funding.

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.

Cost and finding a good therapist.

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

The poor bedside manners of psychologists is a big factor in this.

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

"Take everyone's story as real and listen. Sometimes all we want is for someone to call us and say 'how are you doing today?' Being a carer is very stressful and underpaid and we cannot afford the proper treatment such as paying for a psychologist or counsellor. It is great that you can access the mental health care plan but that does leave you still with out of pocket. As small as that out of pocket may be, it might not fit the budget. "

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

Have people understand what Carers are faced with every day.

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?

Not sure

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?

I think everyone should have access to the system. I don't think patients should be charged to do the paperwork with a nurse and then have a doctor sign off on it. This happens at my clinic. It's a private clinic. It is a huge amount of money for paperwork that takes 5mins to do. Both the nurse and doctor are able to bill for their time.

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

It's hard to say

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

I am a mother and carer of 2 of my kids. My husband and I battled the NDIS system for over one year. We had such poor treatment from them concerning my eldest daughters application. We felt though she was being discriminated. We felt that people within NDIS didn't know about her condition because it is so rare and so they just put her in the too hard basket. We do so many hours of administration work for both our kids and we feel like there is not enough support.