

SUB.0002.0016.0031

Royal Commission Submission

[REDACTED]

Carer of a young person with Anorexia Nervosa and other mental health issues

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

I am writing as a carer of someone who has had a number of mental health challenges, primarily an eating disorder and generalised anxiety disorder/social anxiety. I am also writing as someone who has in both a voluntary role and a paid role, been required to harness the stories of the journeys of others to advocate, develop resources, train health professionals and provide interventions for carers of those with an eating disorder.

Our story in many ways was not the worst of stories you will hear at the Commission. Our daughter had extremely high anxiety all her childhood for which I sought treatment at various stages to no avail. She struggled with change, social situations, wanted to chop her budding breasts off [REDACTED] frequently yelled and screamed at home and had huge difficulty sleeping. Despite all this she was a star pupil, a representative athlete and to the outside world a very responsible, conscientious, capable person, highly regarded by teachers and coaches. This made accessing support for her challenges extremely difficult as they were not visible to anyone outside the home.

Diagnosis

In [REDACTED] aged [REDACTED] she went on a World Challenge trip to Nepal where she hiked a strenuous trail, worked in an orphanage etc. The kid who left on the plane and the one who stepped off the plane 4 weeks later were two different kids. The one who returned was 4 kg lighter, but within days it was apparent something more was up. She was stressing about the upcoming Xmas meals and festivities, started running obsessively, sorted out our entire pantry into alphabetical order, wanted to control my food shopping list, developed an interest in cooking. More importantly she was becoming socially withdrawn, wasn't sleeping and finally, when asked in mid January [REDACTED] what she would like for her birthday, said she thought she needed to see a psychologist as she couldn't sleep at night worrying about what she was having for breakfast and then couldn't relax during day worrying about all the next meals and what exercise she had to do.

[REDACTED]

We were so blessed that she was so open and could identify what was going on in that early phase. And so we thought it would be simple to fix or get treatment for. I booked an appointment at the GP who theorised that it was OCD or anxiety disorder and referred us to a clinical psychologist who attempted to treat the OCD and anxiety. No-one took any vital signs measurements or suggested that we as a family step in to start insisting that [REDACTED] eat or not run. Within a few weeks, as the weight continued to drop off, [REDACTED] complained of feeling unwell and having chest pains and finally, had an episode at school where she felt faint. I immediately returned her to the GP who for the first time ordered an ECG and Bloods, and sent off a referral to the [REDACTED] Eating Disorders Program. The nurse who did the ECG did not appear concerned with the results and sent us home, whereupon for the next 3 days [REDACTED] trained for basketball on the Thursday, played the Friday, did a Zumba class on Saturday and more training on the Sunday. On the Monday, I received a call from the Children's Hospital to say could I please collect [REDACTED] from school and bring her to the emergency department immediately. On arrival at the emergency department, her heart rate was critically low, her blood sugar level almost non-existent and we finally received a diagnosis of Severe Anorexia Nervosa only 10 weeks after she returned home from Nepal.

Lesson for the system

GPs need to suspect an eating disorder and investigate ASAP – do not watch and wait. While our wait was brief compared to the many stories I have been privy to, it posed a serious risk to [REDACTED] life and was gut-wrenching for us as her parents, that we had somehow let [REDACTED] become critically unwell on our watch, through lack of nutrition and overexercise. It took a long time for me in particular to be able to get over that visceral horror and not be hypervigilant with [REDACTED] eating.

Many more families than need to experience this as part of their help seeking journey. Up to 40% of admissions into the [REDACTED] outpatient eating disorder program come into the program via emergency and a hospital admission for medical stabilisation. That means the child/adolescent has been allowed to become so unwell that their hearts are compromised and at high risk of stopping. This can be prevented by taking parent concerns seriously, encouraging families to support normalised eating and exercise minimisation – if the child does not have an eating disorder, no harm done. Normal eating and relaxing are not a dangerous medication with side effects. If the child finds this is incredibly distressing then you know what you are dealing with. However, the prevailing advice is watch and wait, don't be the food police, this is a phase and so on.

Treatment

After 5 weeks of medical stabilisation, we were sent home to do Family Based Treatment, which is an evidence based treatment for anorexia nervosa in under 18yr olds. It required us to feed our daughter 6 times a day an extraordinary amount of food, which she was beyond terrified of. We also had to restrict her physical activity while her brain was screaming at her to stop any 'fat globules multiplying all over her' (her words, not mine). I slept with her for 5 months. I was covered in bruises from her violence, she would scream and abuse us constantly. She was medicated on anti-psychotics and SSRIs to try and enable all of us to get some sleep and to take the edge off her thoughts. It could take us 12 hours a day to feed her. We did not take our eyes off her for approx. 6 months apart from the time she was in a classroom. If we did, her AN would tell her to do 100s of star jumps and sit ups. She would get stuck in front of a mirror unable to stop checking her fat. She had to tap all the dishes and things on the table 3 times before she could eat. Our previously sane child was nowhere to be seen.

Once a week we would meet with our FBT therapist to check on her weight and strategise for the next week. Over 6 months she gained 14kg through us feeding her 100% of her food 100% of the time – we did not miss one meal or snack over that time. 6 months in we had to leave RCH as that was the length of

the treatment programme and we were not referred to any other program. At that stage [REDACTED] was still not able to put a mouthful of food in her mouth without us requiring it and it took a further 18 months of us supporting her to return to independent eating, normal exercise and a return to healthy mind - with no treating team or monitoring apart from paediatrician visits to monitor medical status. And we are the lucky ones.

[REDACTED] was also still suffering from her other mental health concerns of social and generalised anxiety which seemed worse after the AN than before. We sought private psychiatrist and psychologist support, however almost no one was interested in our input anymore, despite how closely we had been involved in treatment and understood our daughter. My daughter found them to be largely ineffective as they would say 'dumb things' like why do you eat so much, why are you stressing if you lose weight. After a severe episode in 2017 where we called the CATT team and had the police come due to her physical violence where they issues a Safety Notice which prohibited her from being violent to me for 12 months. This prompted another effort to find a private psychiatrist ([REDACTED] was not deemed unwell enough to be in public mental health) and after a significant waiting period we were able to see a lovely psychiatrist who was a family therapist. He saw our whole family even though [REDACTED] was now 22 and it was extraordinarily effective. We strategized effective boundaries, tools for [REDACTED] medication options and started exploring the notion that [REDACTED] may have Autism Spectrum Disorder which would explain a lot and I had thought since she was a pre-schooler.

From then until now, [REDACTED] has managed her mental health much more effectively through lifestyle changes and reducing her high expectations. Conversely, she has completed university and is now working as physiotherapist in a country hospital, living on her own and participating socially in a whole range of local activities. She is now doing everything we ever wanted for her before she got sick and which we thought would be lost forever.

In order to support her, however, early on I had to take unpaid leave for 5 months from my role as a CEO of a not for profit. When I returned my husband took 3 months off work. We organised a mortgage repayment holiday – which in the end had to be repaid as a lump sum when both back at work. We could not afford this, so sold our house to get rid of the mortgage. I ended up resigning after a further 6 months under duress from my position as the demands while caring were too high and my Board were unhappy with my performance. I ended up needing some psychological therapy for me as well as medication.

What was critical was that I sourced and accessed informal positive peer support from the early days of my daughter's illness – online peer support when we couldn't get out of the home, catch ups with other local parents that I met through treatment or online forums, and over time connections with many families. Meeting families in the same predicament, those who are just a bit further along the recovery journey gave me hope, hundreds of helpful practical tips, and a sense that if they can do it, so can I. I was not offered this at any stage of the treatment journey. I credit this peer support with giving me the strength and tools to help my daughter effectively.

Our family has taken a beating through this and while still intact, there are flare ups and overreactions to a lot of scenarios which didn't exist beforehand. Our older daughter has been significantly impacted, missing a lot of support from us during formative years for her.

Lesson for the system

- Recovery from an eating disorder takes a while and it would have been helpful and less stressful, if we had been supported with a clinical team to a fuller recovery e.g. 2 years

- Respite and support while doing FBT would have made a world of difference to our family. We had 1 hr a week of therapy/FTB coaching for a serious mental illness.
- Once in the adult system, significant mental health challenges become really difficult to navigate with me as carer playing a key care coordinator role, creating our own 'flawed' mental health team and not being able to access services like CATT in a crisis. And generally not being asked for my opinion, take or engaged with at all. I was still paying for all treatment, I was supporting my daughter on a daily basis and working really hard to support her through to a life where she could fulfil all her potential. With our support and very little support from the system since our treatment at RCH, she is now a highly functioning young adult who will contribute significantly to the economy, our health system and society in general. There was a very high chance 8 years ago of this not being the case.
- Always include the family as a given. Ask us for the history. Involve us in strategizing around solutions and respect our opinion. Provide us with support for our own mental health.
- Provide access to carer peer support throughout the journey from diagnosis to recovery as a key required component of the treatment process.

My roles since

[REDACTED]

Workwise, in [REDACTED] I dusted myself off and reinvented myself somewhat. I was privileged to be able to combine my previous professional life in health change management and population health with my new passion for eating disorders. [REDACTED]

[REDACTED]. During this time I have consulted with over 100 families in public mental health services and been involved in the clinical consultation provided for over 500 cases at [REDACTED]. I have provided education for clinicians on the role of families and carers, and developed resources that services and clinicians can use to assist families better.

Over that time, it has become apparent to me that families of those with an eating disorder experience extremely high levels of frustration with the eating disorders system. Families caring for a first episode eating disorder with an under 18yr old largely get a good service from our CAMHS/CYMHS system. Those with additional mental health comorbidities, suicidality or family challenges can struggle within this adolescent system especially when both psychiatric and physical inpatient is needed. But the challenges in the under 18 system pales into comparison with the over 18 system. Suddenly the person with the illness is accorded agency when still as impaired in their thinking as they were when less than 18. Getting an adult with an eating disorder to be treated with the same urgency as an adolescent is next to impossible. People are allowed to get much sicker before they can access appropriate support, the specialists services won't take them unless they volunteer for treatment and don't have current comorbidities or suicidal ideation. Psychiatric services won't support the full nutrition needed their mental health. Families are usually completely locked out of a supporting role. Emergency departments discharge clearly unwell people when they say they will eat when they go home without reference to families' advice about inability to eat at all. For the most unwell with minimal insight, they are being held by a GP and maybe a private psychologist – leaving families to bear the full responsibility for making calls

[REDACTED]

