

Our 18-year-old daughter was diagnosed with the eating disorder anorexia nervosa in August 2014 at our closest hospital here in Melbourne. She was recently discharged, given she could no longer legally be forced to attend appointments. Over a period of almost 5 years she endured over 130 outpatient appointments and spent a total of over 6 months as an inpatient. I wish I could report that she is now better. However, I can't. She still has a long way to go in her recovery and experiences medical and psychological complications as a result of the prolonged and chronic nature of her eating disorder. Having water-loaded at times in excess of 2 litres of water before appointments, in order to increase her weight and over an extended period of time, she now appears to have bladder incontinence. She has primary amenorrhoea, bradycardia, a suite of gut-related issues and is always cold, even in the summertime. The hot water bottle she has against her body to stay warm has left a 'snakeskin' pattern on her thighs and abdomen. She is unable to fully participate in activities most youth would take for granted. Indeed, the eating disorder has robbed her of a life she can never get back. She has spent her entire life at secondary school with the illness.

The effects of the eating disorder on our home life (my husband, 16-year-old son and myself) have been profound. Cooking and eating meals together is an ongoing challenge, having visitors, including extended family, is an ordeal and family holidays are non-existent since going away together with an eating disorder to keep us company is too stressful and certainly not the fun holidays are meant to be. The only way to have a break away is to separate the family. The guilt I live with for not having been able to get our daughter better is painful and debilitating. Trying to fix the eating disorder consumes my life and I am finding it hard to focus at work and in general. Living with someone with an eating disorder robs one of any spontaneity and joy in life. I myself experienced an eating disorder in early adulthood which took me 10 years to recover from. I had never expected to encounter such a beast of an illness again in my life and especially not in my children. I have since learnt that there is evidence of a disposition to acquire the illness being hereditary.

So that is my story which I wanted to share with the Royal Commission. On the basis of my experience, I have the following ideas to help prevent mental illness (in this case eating disorders) and to support people to get earlier treatment and support before the illness becomes overwhelming.

GPs need training to be able to recognise eating disorder behaviours so that cases can be immediately referred to appropriate treatment. In our daughter's case, almost a year passed between her first GP appointment and being diagnosed in hospital. Had the GP been trained she would have been treated sooner, before neural pathways were set and behaviours much harder to modify.

Schools also need better facilities for managing students with eating disorders. Long before the diagnosis, when my daughter was in Year 7, I had called the school psychologist during my lunch break at work to express my concern. I was promptly told that my daughter would have to seek help herself due to confidentiality which left me feeling powerless. In addition, schools need facilities whereby students can eat their snacks/meals in a warm, safe and private environment whilst in recovery.

Treatment options should be more varied because 'one glove does not fit all'. We were encouraged to force feed our daughter on discharge which may suit families where the parents rule with an iron fist but in our case it simply didn't work, in spite of our efforts. When our daughter was 15 we had an opportunity for her to start a day program which might have been an alternative to inpatient treatment. However, she didn't get beyond the rigorous assessment process because she refused to be reintroduced to meat! I have since heard that the program now accepts vegetarianism which is a good sign, but too late for our daughter.

Treatment programs should enable the patient to get to a healthy weight before discharge, so that they have the best chance of making a success of eating at home. In our experience, being so underweight hindered recovery because our daughter was discharged at 75% or less of a healthy weight. More beds should be allocated to eating disorder patients so they can be readily admitted, especially in the early stages of the illness. Information needs to be provided on all available treatment options in both the public and private sectors.