Submission to the Senate Inquiry on Better Access to Mental Health

Anorexia nervosa – H's story

In late 2009, my 18-year-old daughter, H, who was living and studying in , rang me to say that thoughts about food and calorie counting were becoming all consuming and taking over her life. I arranged for her to see a psychologist, but over the next two months, despite my best efforts, she continued to get sicker and sicker until by early 2010 she had developed anorexia nervosa.

It took 6 or 8 weeks before we finally stumbled upon the care that she required. She began seeing a fabulous specialist dietician and psychologist who worked closely together as a team. In late January, when H was eating little more than black tea and celery, the dietician, announced that if she lost a further 2 kg, she would put her on a waiting list for hospital admission. Everybody that we spoke to, including several of H's friends who had had serious eating disorders in the past, were adamant that hospitalisation should be avoided if at all possible. This provided the motivation that she need to begin the process of refeeding, without doubt the most traumatic experience I have ever been involved with in my life. On her 19th birthday, H started taking antidepressants and valium to help cope with the extraordinary anxiety generated by refeeding and she started on a 6 meal-a-day meal plan that we negotiated with the dietician. During this period, H was seeing the dietician twice weekly for hour-long appointments: without this support, hospitalisation would have been inevitable. Gradually, the speed at which H was losing weight slowed and, with 0.5 kg to spare, stopped and she very slowly began to regain weight.

Treatment and refeeding

It took over 3 months, however, before she was able to eat anything without extreme anxiety. It is almost impossible to describe just how traumatic this experience was for H. She regularly scratched deep welts into her skin during meals without even realising that she was doing it. It was only later, when they started to hurt, that she found them. Relatively early in this process, a friend of mine who had worked for 40 years as psychiatric nurse, including stints at , as head of a CATT team, and at hospital, sat with her during a meal and became so alarmed about her mental health that he arranged for her an emergency appointment with a specialist psychiatrist, who adjusted her other medication and prescribed anti-psychotic medication, but allowed the process of 'therapy' to continue with the psychologist. I know that the prescription of 'off-label' anti-psychotics in the treatment of anorexia has received some criticism in the press recently, and even though H didn't like the way they made her feel and stopped them earlier than the psychiatrist would have like, they were helpful. They quietened the shrieking chorus of self-hatred that ran perpetually in her head, reaching a crescendo of violence during meals, and provided just a little more space in which she could start the long hard work of dealing with the underlying causes of her disorder. During this acute phase of the illness, H needed all the help she could get.

For the next 18 months, H continued to see the dietician and psychologist weekly, and the psychiatrist every 2 to 4 weeks. In the early phases, the dietician was the most crucial member of the team, but as H gradually became sufficiently well nourished for something approaching normal mental function to resume, the psychologist assumed an increasingly important role. I have the most profound respect for the professionalism and competence of these young women. In a very real sense, H owes them her life. She is now doing well: she recently moved into a flat, is working full time and is eating, if not normally, at least adequately. She has stopped seeing the psychologist and only sees the dietician and psychiatrist every 6 to 8 weeks, just to check that she's still on track.

The psychiatrist was also played an important role in H's recovery, but she never developed the strong bond with him that she did with the other health care professionals.

Inadequacy of current Better Access Funding

Until H became unwell, I had always thought that under the Australian health system, while you might need to wait, possibly even longer than was really ideal, for elective surgery, if you were genuinely and acutely unwell, you would get the care that you needed. I now know better. I was appalled to discover that H was eligible for 5 Medicare-funded dietician appointments per annum. This allocation lasted for less than 3 weeks: after that I paid either $100 for an hour or $60 for a half-hour appointments (as H improved the session became not only less frequent, but shorter).

Then I discovered that she was only entitled to 18 psychologist visits. So for the second half of last year, I paid $190 out of pocket each week for psychologist and dietician appointments. Fortunately, I was financially able to do this, but I was very alarmed at how people less well off than I am were able to cope. I asked the dieticians who said that if we hadn't been able to pay, H would have been referred to the , where should would have had an appointment with a dietician every 6 weeks or so, possibly with somebody different each time. This is completely inadequate: I have no doubt that H would have been hospitalised if she had not received the care she did, at great cost to the taxpayer.

Response to proposed changes to Better Access funding

I was, therefore, appalled to discover that under the proposed changes, despite the promise of increased funding for youth mental health services, H would be entitled to less Medicare funding than she had been before.

According to the CAP Allied Mental Health Service Fact Sheet

- 87% of current Better Health users attend less than 10 sessions. Presumably the other 13% of people include those, like H, who are most seriously ill, and who are in most acute need of treatment. How is it fair to **penalise this most vulnerable** group?
- The Fact Sheet suggests that people with 'more severe or complex needs' should be referred to 'more appropriate' mental health services. H's needs were sufficiently complex and severe that she needed access to both a psychiatrist **and** a psychologist. In my opinion, the team of a psychologist and a dietician was the most 'appropriate' care for her, and I don't see why she should have been denied this choice.
- The changes to the program are justified by the current 'tight fiscal environment'. They are, however, is a **false economy**.
    - The standard rebated on a psychologists visit $140.90; for a psychiatrist it is $176.70. In my experience, psychologists actually charge around $150, while

    psychiatrists charge $240-80. Once the safety net is reached, which it quickly is with serious illness like this, the costs to the taxpayer of the later become significantly higher. Forcing people who would rather work with a psychologist to see a psychiatrist is, therefore, the more expensive option.
  - If I had not been able to afford the substantial out of pocket expense, H would have been hospitalised, at considerably great expense than any outpatient or private treatment.
- The areas that are flagged as receiving extra funding – headspace and EPPIC services, for example – would be of no use to H. It is possible that something like this **might** have helped H if she had had access to it in the early stage, although I'm far from convinced. Once she became ill, however, she required specialist services, with health care professionals who were experienced in the treatment of eating disorders. These people are out there and they really can help – if you can afford to pay.
- This funding model is **inconsistent with our approach to physical illness**.
  - Last year I was hospitalised with a ruptured appendix. There were complications: I spent 18 nights in hospital over the next 3 months. The average hospital stay for appendicitis is, I believe, 2-3 days. Nobody said that because I need more than this I should pay for the remaining 15 days myself. Why then do we apply this logic to mental illness?
  - We do not say allocate a number of visits on the basis of specialisations for physical illness – you're going to a lung specialist, therefore you are entitled to 5 sessions; you're seeing a cardiologist so you can have 7. Why then do we say that all people who see a dietician, for no matter what reason, are only entitled to 5 visits; those seeing a psychologists get 10. Patient needs will always depend upon the individual and the nature of their illness. This should be recognised for mental, as well as physical illnesses.
- I am not convinced that 6 sessions with a psychologist is enough to deal adequately with any even remotely complicated situation, and **I am alarmed by the general cuts to this program**. But I think it is particularly outrageous that we cannot come up with a system that can distinguish between people who need some help with the challenges life inevitably throws up and people with life-threatening illnesses.

Eating disorders as mental illness

A letter in yesterday's *Sunday Age* newspaper (Kate McConnell, 'Let's talk about…', 18 Sep 2011), called for more discussion of eating disorders as mental illnesses. I can only endorse this comment. Every parent dreads anorexia, but I think it is the physical aspect of this condition that scares people most. I quite simply had no idea of just how seriously mentally ill people with fully-fledged eating disorders are, and I don't think many other people are either. The popular press is full of quick references to celebrities with eating disorders, who simply 'decided' to start eating again; nothing I have read comes even close to capturing the trauma of this condition. Society is full of people with disordered attitudes to food: in fact I think you could say that as a society we have a disordered relationship with food. But this has about as much relationship to acute anorexia or bulimia as feeling a bit sad does with suicidal depression. This is a terrible, debilitating mental illness – far too common amongst our young people – and it should be properly recognised as such and funded appropriately.