

Submission on Mental Health

From a family's perspective dealing with Narcolepsy

I write this submission as a mother, from a heartfelt position as a mother of a 17 year old girl who has type 1 Narcolepsy, a rare neurological sleep disorder that impacts every aspect of her life.

You may wonder why I am writing this submission for mental health yet discussing a sleep disorder, I will endeavour to outline my case in the following submission.

A recent government inquiry into sleep health in Australia, headed by Trent Zimmerman, outlined that sleep and sleep health should be taken as seriously in Australia as diet and exercise. The report detailed that inadequate sleep, either by way of sleep disorders, or through shift work etc was having a major impact on Australia, both financially and mentally.

I was fortunate enough to speak to the standing committee, on behalf of my daughter, to explain that on any given day, her life was unbearable to her, the impact that it has on our family, her schooling and any future chances of employment, potentially costing the Government an unknown amount of money, both trying to help her now and into the future.

Ella was diagnosed with Type 1 Narcolepsy in April 2015, it was as sudden onset, no previous signs of this disease, and completely life changing. This energetic girl, who was on a fast track to play elite sport, could no longer stay awake, would collapse, from Cataplexy, on the soccer field, was no longer able to swim alone for fear of drowning, her life changed in an instant.

From a family perspective, it changed our lives too... we grieved the child we once knew and moved forward with a child that became a little withdrawn, uncertain of her future and where we would end up. The impact mentally that any disease diagnosis has, is bigger than I think people realise. We go about our day doing all the same things, the running kids to school, the shopping, work but always worrying if she is coping today or will it be a day where she no longer wants to be here because it is all too hard.

I have no answer as to what needs to be done, but I feel that with any life changing diagnosis, there needs to be some form of compulsory psychological help. Four years into our journey with Narcolepsy, we are only now getting some help. The strange thing is we have quite often felt, isolated and even when asking for a mental health plan for our daughter to see specialists, we have been questioned and, I wouldn't say ridiculed, but I don't think they (professionals) understand the impact that this has on her life.

Many times, when she is deep in sleep hallucinations, (very sensory hallucinations that occur when going to sleep or just upon waking) and we are trying to reassure her that what she is seeing is not real, she will tell us that she no longer wants to be here, that what is happening to her, as part of this disease, is too much of a hurdle.

Sleep deprivation on any level has a significant impact on your mental status, these sufferers have severe sleep deprivation, it is aligned to being awake for approx. 48-72 hours everyday of your life. Imagine if you can the impact that has on your mental health, every day. It becomes harder to function it, it becomes harder to make decisions, it becomes harder just to even think clearly. All these things will have an impact on mental health.

Mental health, I believe covers a very broad range of things, it is not just your diagnosed psychological problems, it is not just depression. It is the inability to enjoy your life, it is the inability to be seen to be able to participate in normal life, without judgement. It is the pain that families feel when they don't know how to help. It is the pain a mother feels wondering how her daughter will cope with life. It is the pain of not knowing where to turn for help without judgement.

As a mother, everyday is like walking a mine field of mental health strategies, to help our daughter be able to actively participate in life.

I ask you, that as part of any mental health strategies that may come from this inquiry, that you look closely at the correlation to sleep, to sleep health and not just band aid solutions to the current mental health crisis affecting Australia. There are many reasons why people suffer from mental health, many due to other health problems and I think that is needs to be looked at. I also think that it is important to look at medications used to treat other disorders and ascertain what impact these medications are having on mental health as well.

Sometimes it is not just the sufferer, who suffers, it is the family and the extended community. We love our kids and only want the best for them, but sometimes it does all become a little to much even for the toughest person, and without support, without adequate resources, we are all just going through motions, hoping that tomorrow will be a better day.

I hope that, I have been able to give you a little insight, in to the world of sleep and its correlation to good mental health, without good sleep the world gets harder to deal with, with a sleep disorder, it becomes a daily battle.

I would welcome the opportunity to speak with you further on this matter.

Regards

Pamela Bird