

Inquiry into sleep health awareness in Australia

Term of reference to be addressed:

Access to, support and treatment available for individuals experiencing inadequate sleep and sleep disorders, including those who are: children and adolescents, from culturally and linguistically diverse backgrounds, living in rural, regional and remote areas, Aboriginal and Torres Strait Islander.

I am an Australian citizen born overseas. English is my second language. I live in Charters Towers, Queensland.

I was diagnosed as a narcoleptic in 2003 but have been severely symptomatic since early childhood. I have suffered overwhelming daytime somnolence for as long as I can remember. Constantly falling asleep very quickly turns into a rolling nightmare. One's personal agency degrades dramatically. Being routinely exhausted is often communicated as laziness. The literature states the average narcolepsy sufferer, when experiencing a sleep attack, physiologically functions under a sleep debt of two to three days. To say that living like this is devastating is not hyperbolic. Before being medicated I suffered many such sleep attacks daily.

My life changed dramatically in my early 20s when I was finally diagnosed with narcolepsy. It is common for people with narcolepsy to be diagnosed many years retrospectively of the onset of their symptoms. Everyone can look tired. The condition functions under an aesthetic of normality. This is a common and deep frustration among sufferers.

I was successfully medicated with Modavigil from 2003 to 2009. Initially the medication was near prohibitively expensive at over \$300 per box but was thankfully soon added to the PBS. I was fortunate to have had very supportive parents who assisted me financially. I was able to work part-time hours and lived a largely productive life.

In 2009 I started to show signs of cataplexy. I had always suffered an intermittent and odd weakening in the knees when I laughed, or a strange facial relaxation during high emotion but the instances were always brief and I assumed everyone experienced them. I can't recall even discussing this with anyone. In 2010 I started to experience more acute versions of the aforementioned sensations. I experienced this daily and it often required that I sit or lie down for fear of falling. My quality of life was turned upside down. I

struggled to maintain even casual work. I lost my friends, grew severely depressed and life basically turned into a daily misery.

In 2012 I suffered my first full cataplexy attack. Full collapse, no muscle tone. Helpless on the floor. This would become my new reality when experiencing heightened emotion. I travelled from one sleep physician to another and tried several medications with very limited success. I moved in with my mother and went from struggling to maintain a casual job to being unemployed. [REDACTED]

In 2016 I applied for a free trial of a newly available medication called Xyrem. Melissa Jose of Narcolepsy Support Australia had succeeded where all of Oz's many brilliant sleep specialists had not: she made available a frontline medication, accessible to narcolepsy with cataplexy sufferers overseas for decades.

The efficacy of the medication was startling. My symptoms were tamed dramatically, overnight. I experienced a feeling of normalcy such as I had never before. I felt physically unburdened. The usual stuck-in-a-pressure-cooker-with-30kg-backpack-on daily sensation all but disappeared. My sleep paralysis, which had become daily and debilitating, vanished. The severe hallucinations I suffered daily, that had me questioning my sanity, had gone. My mother could not believe the transformation. Prior to my cataplexy I had sported a 28-inch waist and weighed a touch over 60kg. I was fit and strong. During my years of cataplexy suffering I had ballooned to 88kg and languished in terrible health, on top of my narcolepsy with cataplexy symptoms. After being on Xyrem now for going on three years I am back to my old physique. To say that this medication has changed my life is a laughable understatement.

A single bottle of Xyrem costs \$600.00 and lasts me 12-14 days. I have for the past nine months been able to work fulltime for the first time in my life. I work an average of 45 hours a week and am overjoyed at my ability to do so. In another first, I have been able to submit my taxes as a fulltime employee. I am 35 years old. Although I am still terribly fatigued at times it is an absolute holiday compared to my life before Xyrem. I feel, for the first time, like a contributing, mostly self-sufficient adult. That I should only feel this at my age is grotesque.

Paying for this medication means I am still beholden to my mother for intermittent financial assistance. My fulltime wages simply do not cover the costs and though I realise

my wages will increase with advancement the financial burden will nonetheless remain extreme. Xyrem ought to be added to the PBS.

People with narcolepsy type 1 report in large scale similar tales of betterment with Xyrem. We are people who have looked on others our whole lives and wished to be more productive. We hate the moniker of 'the lazy person.' We are driven for having fought extreme challenge all our lives. If nothing else, we can add substantially to the tax haul should we be given reasonable access to a medication that allows us to function normally. Please, please make this lifesaving medication available to us in a manner that is sustainable.