

## Submission for Inquiry: The Sleep Health Awareness in Australia

My name is Laura Thompson and I was diagnosed with Narcolepsy type 1 in February 2017 at the age of 21. Narcolepsy has greatly impacted my life and I hope that an inquiry into Sleep Health Awareness; particularly into the rare topic of Narcolepsy, will be beneficial for many Australians.

Narcolepsy is a chronic neurological condition that affects approximately 0.05% of the population. This condition is the inability for the brain to regulate the sleep-wake cycle. The cause of Narcolepsy is unknown and the average delay for diagnosis is between 8-15 years. There is no cure for Narcolepsy and in Australia our treatment options are limited.

I currently take the maximum dose of stimulant Armodafinil each day, which is used mask one of the most common symptom of Narcolepsy excessive daytime sleepiness (EDS). I also take 45mg of Venlafaxine (Efexor) daily to target the symptom of Cataplexy. Cataplexy attacks are triggered by strong emotions (in my case laughter, anticipation and pride), so the antidepressant is intended to level the emotions to prevent this. Although these medications allow me to keep a job and function as a somewhat normal person, Narcolepsy limits me in many ways. These medications are only masks that hide symptoms and become less effective over time. Sodium Oxybate is a medication that is used in other parts of the world to treat Narcolepsy, however in Australia this is not covered under PBS and extremely expensive.

The education for doctors in Australia on Narcolepsy is also extremely limited. Many General Practitioners and nurses I have seen in the last few years have looked at me blankly when I advise them of my condition. It concerns me that GPs do not know what Narcolepsy is when you provide them with your diagnosis much less identify the problem when someone describes their symptoms.

A sleep specialist is seen to receive a diagnosis for Narcolepsy, however in many other parts of the world it is a Neurologist that is seen. Most sleep specialists in Australia are respiratory focused and do not have the education on the condition of Narcolepsy. As they are not exposed to many patients with this condition they lack the experience in providing treatment options and support pathways.

Support is another huge aspect of Narcolepsy, there is little to no awareness of the condition and people suffering resort to online forums. The mental health and quality of life for those with Narcolepsy is severely impacted and we often feel extremely isolated. We are often reluctant to tell other about our condition due to the lack of awareness and understanding. It is easier to remain silent than explain how it is nothing like the scenes in Deuce Bigalow.

This inquiry is greatly appreciated by those of us affected by Sleep Health Awareness in Australia.