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From: Patric Turnock [mailto:fyi-request-10379-08bfc724@requests.fyi.org.nz]

Sent: Saturday, 25 May 2019 1:11 PM

To: J Ardern (MIN) <j.ardern@ministers.govt.nz>

Subject: Official Information request - What is New Zealand doing to support people suffering from Narcolepsy

Dear Jacinda Ardern,

Firstly, let me say I am extremely proud of the work you do every day and the way you have shown empathy, compassion and care for everyone in this country in the hardest of times has been incredible. As someone who seems like they care about people and their individual struggles, I would like to draw you to attention for one I am facing currently and going forward in life.

I have been struggling with a sleeping disorder for over 6 years now, constantly feeling exhausted, always having to nap, when I do sleep I tend to wake up having horrific hallucinations of someone in my bedroom with a knife and I can't move my body because it's physically locked down by my brain. After a few terrifying minutes, you get movement back in your body and the hallucination disappears. These are some of the symptoms of a disease called Narcolepsy. There are two types to this neurological disease but basically it means your brain cannot regulate your sleeping cycles correctly and you can wake up multiple times a night without reason and within 1-2 hours of waking up you feel excessive levels of daytime sleepiness. You have sleep attacks that make you physically weak and need to take a nap immediately and sometimes have symptoms where your muscles lock down during heightened emotions and can even cause you to collapse.

Since I have been diagnosed with this incurable disease, I have been looking into resources in NZ that can help me. However we seem to have no New Zealand based resources. The one website that I found on google called Narcolepsy.org.nz does not work and there are no support groups online I can find. I have had to join US and UK Support groups for any resources or support with dealing with this sleep/neurological disorder. Bringing me to my request.

What is the New Zealand Government doing to support people suffering with Narcolepsy which can go undiagnosed for many years due to complexity of diagnosis and the cost associated with it?

On average it takes a patient 10-15 years of being physically exhausted and having no answers to be diagnosed. There is a paper Dr Andrew Veale (NZ Leading sleep and respiratory specialist) did in 2010 for the ministry of justice explaining how difficult this disease can be to diagnose and that there needs to be more support and training for GP's to effectively identify and refer clients to the correct specialists to be diagnosed. This is incurable and means that you have to take stimulants (Methylphenidate) every day, sometimes multiple times a day and sleeping pills every night to try get any decent level of normalcy.

As someone who was told for years they are depressed, they need to exercise more, there may be an underlying issue from when I was a child and got checked for everything from thyroid problems, brain tumours etc. I was starting to think I was crazy before I finally spent enough money to get my diagnosis. I would suggest I have spent on top of my health insurance work provides me at a discounted rate, at least \$10k on doctors and tests that were not funded. This is a costly exercise and can go undiagnosed for years. People that don't understand how bad the excessive daytime sleepiness (equivalent of not sleeping for 48 - 72 hours) is think you are lazy, a complainer, depressed and all of these things have effects on people suffering.

Can you advise me if the government has this on their radar?
Is it something that is even getting decent public funding?

For me to get a sleep study done, I had to pay \$2800 out of my pocket to go to Dr Andrew Veale's private practice to get a diagnosis. Approximately 1 in 2000 New Zealanders are affected by this disease and most likely don't know they have it. We need more awareness and funding for this cause to help GP's effectively identify the signs and effectively refer patients to the right specialist so they do not have to suffer for years with sleeping issues and be exposed to more health problems down the track.

I would sincerely appreciate any information you have on this or the health minister does. From a recently diagnosed Narcolepsy sufferer.

Yours faithfully,
Patric Turnock

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