

Dear Policymaker,

I am writing to you in your capacity as my local elected member of parliament in regard to a matter that has a significant impact on me.

I, as well as other members of Hypersomnolence Australia are hoping to garner some much needed awareness for the rare neurological sleep disorder, Idiopathic Hypersomnia (IH). Idiopathic Hypersomnia is a neglected and misunderstood sleep disorder. More attention and research is needed to understand it, at the same level as other sleep disorders such as narcolepsy.

I was diagnosed with Idiopathic Hypersomnia (IH) in 2018/2019 when I was only 34 years of age, but suspect IH has affected me for many, many more years prior to my diagnosis. I have long struggled to feel awake during the day despite long periods of uninterrupted overnight sleep. I was most often dismissed by medical professionals as being depressed and/or lazy - both of which I knew I was not. This period of around 10-15 years of not being taken seriously or believed by medical professionals has unfortunately left me with a general distrust for the medical industry, and likely some anxiety with regard to dealing with other medical issues. Further, upon diagnosis, I was offered zero support for living with this incredibly impairing condition.

Idiopathic Hypersomnia has an impact on nearly every aspect of my life - practically, socially, emotionally, and sometimes psychologically when I am faced with yet another instance of living in a world that is not suited to life with this kind of disability. Because there is no suitable medication I can take that will take away the overwhelming and unpredictable sleepiness I experience, the best way I can manage my sleepiness is to have several daytime sleeps. These daytime sleeps totalling about 3-6 hours in duration are in addition to the 10-12 hours of sleep I get overnight.

After a sleep, as I try to wake myself to resume my day, I often experience sleep inertia or sleep drunkenness which affects my cognition and motor skills. Sleep inertia makes me appear as though I am drunk - my thought processes are severely impacted and I find it near impossible to make any rational decision and often say things which are non-intentional or irrational. I am prone to walking into walls, tripping and slurred speech as if my brain cannot quite wake up. This sleep inertia feeling can last for at least half an hour, but sometimes I cannot shake this drunken feeling for several hours before the overwhelming urge to sleep returns. If the sleep inertia does lift, I am constantly fighting other symptoms of cognition dysfunction.

The ways in which my cognition is impacted are great. I often say things without intention, have trouble remembering conversations, my actions from just moments prior, and important information. This is particularly concerning when I have medical appointments and cannot remember the conversation I just had with the respective medical professional as soon as I leave their room. I am also prone to injury when I'm in the kitchen just trying to feed myself. I have accidentally burnt and cut myself numerous times whilst preparing meals simply because of my impaired judgment caused by IH. I have been in some extremely risky scenarios also because of my significantly impacted ability to make reasonable decisions, agreeing to things I don't want (but don't realise in that instant) and distractibility. Due to the problematic feeling of never feeling awake with IH, it is incredibly difficult for me to complete everyday activities including my household chores, preparing meals, shopping, attending appointments and administrative tasks such as making or answering phone calls, sending emails, and making appointments. It is incredibly difficult to attend social functions, particularly in the evenings and/or when they are a distance away from home. Therefore I often miss out on important events which might be key celebrations for family and friends. Travelling away from home is hard to do as I need a quiet and comfortable space in which to sleep,

and that is not always available even with friends I think will understand my needs. I also experience significant sensory issues relating to touch, sight, sound and smell, and become particularly agitated when in crowded or noisy spaces.

The window of “wakefulness” on a better day is small. I find that if I have been awake for around two hours, I rapidly decline back into that sleep inertia feeling. This can be fairly problematic for example if I am out and waiting for a specialist appointment and the doctor is running late. By that stage, I am already dozing in my chair waiting for him and become emotional with sleep deprivation by the time I am called. I need someone to drive me home. It can also be problematic in the immediate sense of just trying to ensure my most basic needs are being met - that I am clean, well-fed and my home is clean. Usually, I cannot keep on top of all these things because, besides my ageing mother who can help on occasion, I do not have any kind of external support available to me.

Because of this disorder, I have not been able to work for four years. It is unlikely I will ever be able to return to work - certainly not with the current lack of research to help support those with IH with suitable medication and/or a cure. As such I rely on the Disability Support Pension (DSP) to pay for my most necessary living expenses. However, being able to become a recipient of DSP was certainly not a straightforward process which I attribute in part to the fact that IH is such an unknown disorder that is not easily pigeon-holed into the impairment tables.

Idiopathic Hypersomnia (IH) is a complex disorder which affects me in so many different ways. It is my hope, that as my member to Parliament, that you will consider what a life with IH is like, and that on my behalf you will push for appropriate support and furthered, meaningful research in this area.

What is Idiopathic Hypersomnia (IH)?

Idiopathic Hypersomnia (sometimes referred to as Idiopathic Hypersomnolence in Australia) is a rare neurological sleep/wake disorder. Sufferers have an extraordinary need for excessive sleep yet, despite sleeping for 12 -16 hours (or more) in a 24 hour period, they wake up feeling like they have had no sleep at all.

This results in a range of extremely disabling symptoms including:

- Excessive Daytime Sleepiness (EDS) and the overwhelming need to sleep.
- Impaired vigilance or sustained attention.
- Cognitive dysfunction, especially linked to poor memory.
- Dependence on other people for awakening them.
- Long (>1 hour) unrefreshing naps and profound sleep inertia, known as sleep drunkenness (elucidated as prolonged and extreme difficulty waking up accompanied by confusion, disorientation, irritability, and poor coordination with an uncontrollable desire to go back to sleep. It can also include automatic behaviour with amnesia, ie: performing tasks without consciously knowing it and not remembering you have done them, eg; turning off alarm clocks or answering the phone). This difficulty in transitioning from sleep to wake (often referred to as the time it takes to “get going” in the morning) can last at least an hour but may be as long as 2 to 3 hours when severe.
- Despite extraordinary amounts of good quality sleep, people with IH never feel refreshed; they are in an almost constant state of sleepiness.

The pathogenesis of IH is unknown. An autosomal dominant mode of inheritance has been considered by researchers because around 50% of people with IH have at least one family member who also has symptoms. It appears IH may be more common in females. The prevalence of IH is thought to be 0.005%–0.3% but, due to lack of epidemiological studies, biological markers and misdiagnosis of the disease, the real prevalence is unclear.

Though the symptoms mainly begin in adolescence or young adulthood (typically between 15-30 years of age), it is not uncommon for there to be a delay of many years before an accurate diagnosis is made.

IH is a debilitating, lifelong condition often profoundly affecting work, education, relationships, and mental health. This is particularly the case for those without support.

The House of Representatives Standing Committee on Health, Aged Care and Sport inquiry into Sleep Health Awareness in Australia (2018) found that new drugs and novel medical technologies are urgently needed for people suffering from disorders of hypersomnolence. In the Chair's foreword of the report, Bedtime Reading, Committee Chairman Mr Trent Zimmerman said *"narcolepsy and associated conditions such as idiopathic hypersomnolence can have a debilitating impact on a person's quality of life. There is a need to improve the awareness of these conditions both within the community and among medical practitioners. Further consideration should be given to emerging treatment options that may provide some people experiencing these conditions the opportunity to improve their quality of life."*

Despite this, nothing has been done. There is no research being done in Australia. There is no formalised education or training on Idiopathic Hypersomnia in the sleep specialty curriculum. The Royal Australasian College of Physicians acknowledges the limitations in their training in the 'Sleep Medicine Advanced Training Curriculum', *"There are too few training posts in Australia and New Zealand that can provide broad exposure to and quality training in, the whole range of sleep disorders, particularly non-respiratory sleep disorders"*. And there are currently **no** medications on the PBS for IH. There are medications (including Pitolisant, Solriamfetol and Xyway) being used to treat the symptoms of disorders of hypersomnolence, including IH, in other parts of the world that we do not have access to in Australia. This is a significant problem because the medications which are available here are not suitable for many people. Side effects prohibit a large number of people from using them, they don't address many of the symptoms of IH and their long term inefficiency leaves some people without any options.

Hypersomnolence Australia (HA) has participated in The House of Representatives Standing Committee on Health, Aged Care and Sport Inquiry into Sleep Health Awareness in Australia and the more recent (2020) Inquiry into the Approval Processes for New Drugs and Novel Medical Technologies in Australia, with a particular focus on those for the treatment of rare diseases and conditions where there is high and unmet clinical need. HA has also approached the Australasian Sleep Association (ASA) on numerous occasions about the aforementioned issues, dating back to at least 2014. However, apart from having various ASA members agree that something should be done, nothing has been achieved. People with disorders of hypersomnolence understand that things take time however it is not acceptable for Australia to be so far behind the rest of the world.

People with IH desperately need more awareness, access to better treatment options and they need more support to manage their day to day lives.

Hypersomnolence Australia (HA) does its best to provide support, information, and advocacy for people with IH. However, they are extremely limited due to a lack of resources. HA does not receive funding from any source and they do not charge membership; they provide their services completely free. HA hosted an IH and Narcolepsy Education Day in Brisbane on 10th April, 2022. This was a very worthwhile event, attended by both medical professionals and members of the IH and Narcolepsy patient communities. The event was funded primarily by people in our small community. The general consensus on the Education Day was that patients often receive little or no information when they are initially diagnosed with IH. They are left feeling confused and wondering how they are going to manage the rest of their lives. HA would like to meet this need for information by producing an educational resource for doctors to give to patients when they are first diagnosed. This would be vetted by medical advisors and answer the many questions patients have from the outset. We would also like to curate more events like the Education Day but we can't do any of this without financial support.

Who is Hypersomnolence Australia?

Hypersomnolence Australia (HA) is the only not for profit organisation in Australia, and was the first in the world, to specifically represent and support the neurological sleep/wake disorder Idiopathic Hypersomnia (IH). Its primary purpose is to support the medical community work toward a better understanding of IH, effective treatment options, support for people affected by IH and raising awareness and educating others about hypersomnolence disorders. HA's goal is to change not just the process to diagnosis but also the level of care and services available to patients post diagnosis. However, HA relies solely on donations to survive. This means that the resources and support it can provide is limited. Please add your voice to our plight by engaging with our social media and consider making a donation to support our work. Learn more at <https://www.hypersomnolenceaustralia.org.au>.

References:

1. Dauvilliers Y, Bassetti CL. *Idiopathic Hypersomnia, Principles and Practice of Sleep Medicine* (Sixth Edition) 2017, Chapter 91, pp 883-891.e4.
2. Trotti LM. *Waking up is the hardest thing I do all day: sleep inertia and sleep drunkenness.* Sleep Med Rev, 35, 2017, pp. 76-84.
3. Vernet C, Arnulf I, *Idiopathic hypersomnia with and without long sleep time: a controlled series of 75 patients,* Sleep 2009 Jun; 32(6): pp.753-9.
4. Lammers G, Bassetti CL, Dolenc-Groselje L, Jennum PJ, Kallweit U, Khatami R, Lecendreux M, Manconi M, Mayer G, Partinen M, Giuseppe P, Reading PJ, Santamaria J, Karel S, Dauvilliers Y. *Diagnosis of central disorders of hypersomnolence: A reappraisal by European experts.* Sleep Medicine, 2020.
5. The House of Representatives Standing Committee on Health, Aged Care and Sport, inquiry into Sleep Health Awareness in Australia, *Bedtime Reading*, 2019.

Written by Trinity for the [IH Awareness Project 2022](#)

The IH Awareness Project has resulted in over 50 letters going out to politicians around Australia. The aim of the project is to create awareness of IH and the impact it has on the lives of those living with IH and their family. By sharing our stories and relevant information about IH with the politicians entrusted with representing us we hope to influence policy making in a meaningful way.

