

Dear Policymakers,

Firstly, thank you for your time in reading this letter. I am writing to you to help raise awareness of a condition called Idiopathic Hypersomnia (IH), to be an advocate for myself and others with this condition, who have little to no viable options for treatment here in Australia compared to the rest of the world. We would like to change that, and for that we need your support. The latter part of this letter details a bit more about the condition and the current landscape of struggles we are facing in gaining support towards this condition in Australia.

I am not a person who likes to draw attention to myself and focus on my struggles, however the truth is that I do struggle, and it won't get better unless we voice these struggles so we can bring about change. The effects of living with IH affect me every day, beginning with the daily struggle of awakening from sleep for the past twelve years, since the onset of my condition when I was 18 years old. It takes an enormous effort to pry my eyes open when the alarm goes off so that I don't fall back to sleep. I set a minimum of three alarms each night because I know the feeling of the impending struggle that awaits me in the morning to try and get going on that first alarm. I feel like I could sleep indefinitely. I need an average of 11-12 hours sleep per night to take just the edge off the feeling of sleepiness that is always there, but who has that amount of time to dedicate to sleep when there's work to be done, dreams to be chased, life to be lived ... I don't want to sleep my life away. Prior to the onset of IH I was a highly motivated morning person, even in my teens I would check sunrise times and set my alarm so that I could get out and enjoy the day to its fullest; my heart longs to be able to be that person once again.

Day-to-day living with IH means that you get used to falling asleep in public (in lectures, meetings, cinemas, public transport) and you'll often go into a 'trance-like-state' falling into microsleeps while attempting to read/do sedentary activities (for leisure, work, or study). It also means forgoing simple pleasures like being able to lay down to watch a movie because you can't trust yourself not to fall asleep.

At the age of almost 30 I know that the true extent to which IH can severely impact my life is yet to have its full effects. I am fearful that I will never be able to hold-down a full-time job; I have been burnt out more times than I can remember and have never held a full-time job for longer than three months, always requiring a huge amount of recovery afterwards.

I am fearful that I might never be able to have a family. I am happily married, and my husband would like children one day, however as it stands, I am overwhelmed by the thought of how tired and incapable I might become with the inevitable sleep deprivation that comes with having children, and what that could possibly do to our relationship.

When life demands have been high in the past I have been recommended not to drive by my sleep physician due to safety and legal concerns. This meant that I had to give up my job as I had no way of

getting there. The standard treatment I was offered was dexamphetamine; likened to pushing the accelerator on a car when the handbrake is on. More appropriate medication is available overseas, and more research is needed into the cause of these symptoms, not just a band-aid approach.

I'm forever grateful that I have the loving support of my husband, I cannot imagine how hard life must be for those who do not have a support network to help them. We essentially survive on one salary, plus the small amount of casual work that I do, however I would love to be able to contribute more as it shouldn't be up to my husband to carry all the burden.

On a final personal note, as a highly passionate health and science graduate I dream of being able to make a real difference in the world one day. As an overachiever growing up I had so much potential – I only hope that one day I can be enabled to live up to that once again with your support of raising awareness and improving access to treatment options for those affected with Idiopathic Hypersomnia.

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.
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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.
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Written by Jane 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.

