

Dear Policymaker,

My name is Katarina. I want to bring your attention to a disorder, Idiopathic Hypersomnia (IH) that I, and many other Australians have that receives little to no understanding or support from our family and friends, local community, and local or state government.

I was diagnosed with IH in 2019 however I have struggled with symptoms for many years prior to that. I had aspirations and I fought so hard to realise them but school was such a challenge for me. I would fight so hard just to wake up, then the next challenge would be to stay awake long enough to get dressed and get to school. But I was typically home by midday because I just couldn't stay awake. I would often sleep through dinner; in fact, it was not usually for me to sleep right through until the next day when the vicious circle of having to wake up all over again would begin.

Not much has changed since my diagnosis. I still need enormous amounts of sleep and yet despite all this good quality sleep it is like my brain hasn't registered it at all. I *always* feel like I haven't had any sleep. I *never* feel fully awake. Medication has only reduced my sleep by a little. I still require at least 8-9 hours sleep every day. Medication however does nothing for the horrendous sleep drunkenness and sleep inertia I experience every time I try to wake up.

Imagine what it would be like waking up from a general anesthetic *every morning*. That is what it is like for me. I have my phone alarm set to go off every 5 minutes. I also have an alarm on the other side of the room but none of that matters. If I don't sleep through it all I will turn them off without even realising it and just keep on sleeping. If my partner or mum does not physically wake me up, I don't wake up when I am supposed to, it's as simple as that. I hate going to sleep knowing that if someone doesn't physically wake me, I don't know when I will wake up. I get angry at myself that I can't just get up like a normal human. I hate the fact that I cannot be normal in the morning. I don't like that I have to rely on people.

After my mum or partner wake me, they must make sure I take my medication and they must ensure I stay awake. I literally stumble out of bed. My head is heavy, it feels like I'm in a dream. My legs are sore. I am so unsteady on my feet, uncoordinated and confused. My partner has put bubble wrap over some of the corners of furniture because I bump into corners and doorways. I bump into corners and doorways. I can't do my make up until my medication kicks in because I end up looking like a clown. I find it difficult to communicate with people. I don't understand what is being said to me and I struggle to form sentences in my brain and then when I try to speak it often doesn't come out right. It is so bad and can last well over an hour. I have had days where I don't feel like it has lifted at all. I can go through whole days completely unable to function. Imagine what that would be like and then knowing that going to sleep will *not* help you feel any better.

This is one of the things that is so important for people (including doctors) to understand, it is not like insomnia or some thing else that causes you to feel sleep deprived because in those situations you feel better once you sleep. People with IH do not have the benefit of sleep. There is nothing worse than hearing people say things like 'I wish I slept as much as you.' or 'you're so lucky!' NO, I'm not lucky and I hate it, I feel as though I'm missing out on so much of my life because all I want and need is sleep, and yet sleeping *never* makes it feel any better. I'm constantly exhausted!

I have to literally push myself through every day. I fall asleep on the bus to work. I fall asleep at my desk. I have trouble concentrating. I have difficulty with my memory. The fatigue, the brain fog, the constant need for sleep is relentless. I never get any reprieve. I'm so saddened by the life I am missing out on. I'm hurt by the judgement and the conflict that is caused by people who judge me. I am not lazy. I am not boring and I am not depressed.

I know I am not alone when I say people with IH need more understanding when it comes to the medication we need to take. Many of us find dexamphetamine (Dex) is the only medication that will help us wake up and somewhat function during the day. The stigma associated with this medication is so unfounded. People need to understand that it is virtually impossible for someone with IH to abuse this medication because Dex does not affect people with IH in the same way it does an ordinary person. It doesn't matter how much Dex someone with IH takes they will never feel fully awake. Besides being awake doesn't make us feel any better anyway. We simply use a small amount to help us wake up. We may get a few hours of pretty crappy wakefulness and then we are back to struggling to stay awake before another marathon sleeping session which ends with us having to once again fight to wake up again. The stigma with regards to our medication must end.

Short of a cure or even medication that addressed the cause people with IH need others including family and employers to be more understanding and more helpful and supportive. We also need practical support. I barely have enough quality wakefulness to take care of myself. I have no time or ability to clean my house, do my laundry or shop and cook properly for myself. I suffer a lot because of this. IH has such an enormous impact on every aspect of my life including my physical and mental health so a psychologist and specialist that doesn't cost half my wages would be nice too. No, the public health system doesn't suffice. Apart from the wait times IH is a little known disorder. There are few health professionals that know anything about IH much less have any experience with regards to how it affects sufferers. And no, IH doesn't qualify for NDIS support. I don't know of any support services that are available to people with IH.

You can help to change the situation for people living with Idiopathic Hypersomnia by spreading awareness, providing support to Hypersomnolence Australia (see below) and, contributing to the establishment of policies that will provide people with IH a more secure and optimistic future.

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:

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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, Lecendreuxi 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 Katarina 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.

