

Dear Policymaker

I am writing to you in the hopes you will be able to help us bring more awareness nationally (and globally) of Idiopathic Hypersomnia (IH) and the people and families it impacts.

You may have heard of IH, or perhaps you haven't but may be more familiar with Narcolepsy. Whilst Narcolepsy is much better known, and the sufferers have access to established and accepted diagnoses and treatments; sufferers of IH struggle to have their condition recognized and treated because it is not well known.

I wanted to share with you my experiences of living with IH which I finally had diagnosed in 2018/2019, aged 39. Until it was diagnosed, I had lived life completely unaware that this condition was the reason I have had no energy every day of my life since first striking me in my latter high school years. It crept in probably in my 10th grade and I assumed that it was part of aging and the stress of exams and school becoming more serious than the preceding 10 years. I also assumed everyone else was the same and just managed it in their own way. I had seen my mother fall asleep mid-way through doing things on a daily basis so equated this as normal. Of course, I now know that she has probably suffered a sleep disorder herself all her life given there appears to be some hereditary component to Idiopathic Hypersomnia.

Whilst I started High School as an A student, school captain, and athlete, the important latter years fell apart for me as I would come home from school and go straight to bed. I missed homework and did minimal study because I had no choice but to sleep instead. Through my teens and 20s I struggled to maintain friendships and relationships as I found myself so often sleeping through phone calls, forgetting dates/events, not showing up to things, and finding excuses not to go out with friends because I would rather stay home and sleep. Of course, it was very difficult to explain this to friends and girlfriends; and so often they just gave up on me and stopped calling, or worse, would get angry with me and whole groups of friends would write me off because they could not be bothered with me never answering calls or showing up to things.

My life revolves around sleep. Sleep and work.

Living with Idiopathic Hypersomnia (IH) requires disciplined adjustment, impacting all aspects of my life but most profoundly my ability to perform work duties. I consider myself a driven individual and my role and line of work are high pressure, high risk, and I'm required to work 'as required' i.e. It's not a clock on/clock off type role, but one where I'm expected to work as long as it takes to get the job done. IH is a constant struggle to maintain energy and function normally. Although I'm good at my job, the work is harder and takes longer than it should.

The most important part of my daily routine is to go to bed at a reasonable hour to ensure I get a minimum of 9 hours sleep. You might think it strange but I will typically get home from work; change, eat, shower and be in bed between 7:30pm – 8:30pm. Sometimes I may try to squeeze more hours out of the day and may try to read in bed or watch something with my wife, however there are always repercussions for trying to enjoy these "luxuries" and the next day(s) are an even bigger battle than normal. Of course, weekends may see me sleep up to 15hours each night, but even so my wife will try to raise me earlier as I've begged her not to let me sleep my weekends away.

My need for sleep is insatiable.

Having IH makes waking up in the morning extremely difficult as I do not feel at all rested no matter how much sleep I get. I will very often sleep through alarms and turn them off and fall instantly back asleep and later wake with no recollection of having woken earlier. Even having to get up to pee in the night may take me an hour or more to 'wake' to a point where I am able to swing my legs out of bed and contemplate walking to the bathroom. My brain and body are slow to respond and I have to sit up on the bed for a few minutes before I can try to stand. Sometimes I will fall back to sleep for a while, most times I will attempt to stand and then fall back on the bed, but if I get up and going, then momentum takes me crashing to the bathroom staggering and hanging onto walls before I collapse on the toilet – where I will often lay my head on the sink and sleep again. This is called 'sleep drunkenness' and also extends to my inability to properly speak or think in the morning, or to use my hands.

I need to set my alarm early every morning, and multiple alarms, because it takes at least an hour to feel awake enough rise and start my day. I rely on my wife to wake me up and make my morning coffee. Having a hot drink in the morning seems to help a lot with waking, but unfortunately it is a real struggle to pick up and hold the mug and over the years I have dropped it, knocked it over and sometimes even fallen asleep in it and spilled it all over myself and the bed. Sometimes my wife will hold it for me and she will also take my ear plugs out and open the container for them because my fingers won't work. I am in a daze throughout this time and often I cannot engage in any type of conversation as I feel confused, disorientated and need this time to get my bearings. Where I don't have the luxury of fully waking before I get up because my wife is still asleep or not there, I am forced to roll out of bed in the same fashion as I do to go to the bathroom. I will stumble around and perform my morning ablutions on auto-pilot in a semi-wakened state. Sleeping through brushing my teeth and getting an outfit ready.

I have medication to take the edge off my fatigue throughout the day, but it cannot help me to actually wake and get up – which I need to accomplish before I can take my morning medication. Even with the medication I often need one, two or even three naps throughout the day because I feel sleepy and unable to focus, or even keep my eyes open. Working from home is very much a blessing in terms of being able to take a nap when necessary, but on days in the office, it is horrendous trying to hide my fatigue in conversations, meetings or at my desk. At times it gets so bad that my eyes are rolling around in my head and my eyelids flickering as I desperately try to remain awake. My employer and colleagues do not know I suffer from IH – I have not shared it with them, but there are times when I know that I must look like and sound like the zombie I feel.

The rest periods never really feel like I have rested and I continue to feel tired throughout the day. Whilst the daytime naps don't relieve the sleepiness, they do give me a little energy and hence a necessary evil I have learned to plan and manage strictly, by keeping them to 20-23 minutes at a time.

Another difficult part of IH for me is the ability to focus during the day whilst at work. Work meetings can be quite distressing for me as I am often confused and find it complicated to grasp what is being discussed or the requirement of the task at hand. I feel like the pace of the meeting or the tasks required are at a higher level than my brain can process and I am constantly several sentences or more behind the flow of conversation. Because my head so often feels like a thick, sticky fog, I often lose my train of thought mid-sentence and it can be difficult to get back on track. Sometimes I just can't get back on track and am forced to apologise that I've forgotten what was being discussed or what I was going to say. I can also complete tasks and forget what I have done and have to spend a few moments thinking about whether I have completed it or not, then I can forget what I was thinking about in the first place.

There comes a certain time in the day also where I become aware that I'm no longer productive. I think most people at times can be aware of this, but for me this is a daily occurrence is generally before 1pm –

after that everything takes 2-3 times as long and my head becomes an increasing mush of fatigue and desperation trying to get the days vital work activities completed and maintain an air of alertness and composure.

This inability to be able to fully focus on the task at hand or a conversation is definitely an issue my wife has noticed in our personal lives. My wife will often be asking me to focus on what she is saying because it is clear to her that I am confused or my mind is elsewhere. She will often have to repeat things that were discussed previously as I have forgotten the conversation or was unable to focus in the first place due to being half asleep. At times my behaviour has also suffered greatly as a result of trialing new medication with doctors who are not familiar with my condition or needs. Some medication can have significant and unpleasant side effects which has been noticed at home and at work. At other times throughout medication trials my wife observed me not being entirely present and these were strange experiences for me also.

I was fortunate in 2019 to find a Sleep Physician who was close to my office in town and was very understanding and familiar with sleep disorders including IH. Although still hard, my quality of life has improved immensely once he identified my IH and started me on treatment. This was short-lived however as my career took me to Singapore (SG) late 2020 and I essentially had to start from scratch finding a GP who would refer me to a sleep physician. This field of medicine is even rarer in SG than it was in Australia so I have instead been managed here by a neurologist. Due to the strict laws in SG, my doctor is unable or unwilling to maintain the prescription I had in Sydney and so I have been on a roller coaster of trials for other medications he thinks may help. This has been a nightmare in terms of the serious and unpleasant side effects I've experienced, and the upheaval of 'going through the motions' to fulfil the trials and report back on the side effects and ineffectiveness of the current prescription. This is not to say that my prescription in Sydney did not also carry its fair share of unpleasant side effects, but it at least had the trade-off of being more effective than what I have currently. I understand it can be difficult for doctors trying to treat sufferers of IH because there is such variation in response to the limited medications available.

It's important to understand also, that regardless of the effectiveness of the medication, I am yet to experience anything either at home or in Singapore that has fully resolved my symptoms. At best, some medications take the edge off the fatigue, allow me to go on a little longer, and most importantly, give me a little more clarity and focus to perform as expected at work. Despite this, my brain remains a fog throughout the day and there comes a time where medication must cease because the very worst thing, would be for it to impact the sleep I need that night to be able to attempt it all again tomorrow.

I'm sleeping my life away.

I have over the years been deeply saddened and frustrated at what I consider the 'theft' of my life. I see the achievements of others and the energy they enjoy, their ability to charge productively through a day having slept only 6 hours, managing a household and raising a family; and I would be lying if I said I didn't feel some resentment that I don't have those opportunities to just 'do more'.

I am watching the years go by in a blurry fog and I'm gutted at the realisation I'm sleeping my life away. Equally painful is that my debts and responsibilities mean that after sleep, work is the priority in my life, and all else – my amazing wife and family, friendships, and everything else – gets barely a look in and the scraps of whatever attention and consciousness I can muster when not sleeping or working.

It is vital that we have more awareness and study into Idiopathic Hypersomnia so that sufferers can receive the right diagnosis, acknowledgement of its debilitating effects, and the right care and new treatments to give sufferers back their lives.

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>.

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Written by Andrew 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.



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