

TIPS FOR LIVING WITH HYPERSONMIA

Practical advice for people living with idiopathic hypersomnia and narcolepsy, and their carers, and treating doctors.

One of the most frequently asked questions is, "What can I do to help wake up and get going in the morning?"

For many individuals, having someone physically wake them up is necessary. However, establishing and sticking to a daily wake up routine can also be beneficial. *"This is what my bedside table looks like every night before I go to bed. I use a pop top water bottle because I'm in no state to screw the top off a regular one. I'm still horizontal and half-asleep when I take my first dose of medication for the day. Then, I continue to sleep for another hour or so before attempting to wake up for the final time. Having wake-promoting medication in my system already, helps me to get through the wake-up ordeal."* Michelle Chadwick.



Don't compare yourself to others.

Quiet your inner critic. Work on accepting where you are and celebrate your successes. Learn what your individual strengths and limitations are then adjust your expectations of yourself accordingly.

It's ok to say no.

Once you are aware of your limitations, be brave and clear when communicating them to others. Your time and energy are limited, so you need to be self-regarding.

Organise your morning the night before...

... as much as possible. Eg; Prepare your kids' uniforms, school bags and lunches, before you go to bed. Plan for things as far in advance as possible. A task that may ordinarily take one hour, may take 3 hours for a person with idiopathic hypersomnia or narcolepsy. Make lists and set reminders. Feeling prepared reduces anxiety.

Identify when you're most productive.

Pay attention to when you usually get the most done, then plan your most important tasks for that part of the day. Medication may help you feel more alert than you would at other times of the day, but you may also experience a subsequent 'crash' as this medication wears off. Try to plan your days and tasks accordingly.

Grief and Acceptance.

It is ok to grieve the loss of who we were prior to the onset of symptoms. It is ok to mourn who or what we hoped to be, but we need to accept that we may never be that person again. Acceptance allows us to move forward and be grateful when treatments do work. It allows us to start building a life that is suited to our condition. It allows us to create our version of normal and live a life that is free of unrealistic goals and expectations. We can replace self-criticism and struggle with revised goals and more appropriate expectations. It also frees us from the guilt and shame that so many of us feel and that alone has a huge impact on how much happier and brighter our future will be.

About Us: Hypersomnolence Australia is a registered not-for-profit health promotion charity dedicated to advocating, raising awareness, and providing support for central disorders of hypersomnolence, like Idiopathic Hypersomnia and Narcolepsy.



HYPERSOMNOLENCE
AUSTRALIA

TIPS FOR LIVING WITH HYPERSOMNIA

Adequate sleep is very important.

This may seem obvious. While it may be tempting to try to use medication to enable you to participate in life more, it's important to remember that people with idiopathic hypersomnia generally do not operate very well on less sleep (less than they are used to). You may get away with sleeping as much as an average person (7-9 hours) for a day or so; however, doing this for more than 2-3 consecutive days may catch up with you and result in a 'crash'. Many people who've learnt to manage their symptoms still sleep excessively despite medication; they just sleep a little less excessively. Your sleep environment and routines impact your sleep health. Prioritise sleep. Find a routine that works best for you, then stick to it. If naps help, schedule them into your day. Understand how light, especially sunlight, impacts your circadian rhythm and use it to your advantage. Familiarise yourself with healthy sleep hygiene practices then work them into your daily routine.

Give yourself a break from medication.

To avoid building a tolerance to your wake-promoting medication, schedule days where you take a break from it. I do this at least once a week, usually on the weekend, when I don't have to drive anywhere or make important decisions. Some take a week-long medication break, such as when they're on vacation. If you notice that your medication is no longer as effective as it once was, these breaks can help reset your tolerance.

Know yourself and your limits.

You know yourself and your limits better than anyone else. Find a medical professional who actively listens and communicates well. Set boundaries and stick to them.

Diet & Exercise.

Good nutrition, hydration and vitamins and minerals will not magically make idiopathic hypersomnia or narcolepsy symptoms disappear however dehydration, poor nutrition and a diet that is lacking in essential vitamins and minerals will make your symptoms worse or more difficult to manage. That crash you have in the afternoon may not only be caused by the hypersomnia hitting you when your medication wears off, it is also made worse by the carbohydrates (sugar) you have consumed earlier in the day. [Learn more](#) about the effects of dehydration and electrolyte imbalances. Prioritise physical activity like you do sleep and good nutrition. Being highly sedentary, which is often the case for people with idiopathic hypersomnia and narcolepsy, increases the risk of feeling tired and fatigued. Not getting enough exercise and physical activity causes deconditioning of the body's musculoskeletal and cardiovascular systems and depresses mood, all of which lead to fatigue, which in turn can make idiopathic hypersomnia and narcolepsy symptoms worse or more difficult to manage.

Self-care.

Practicing self-care benefits our physical, mental and emotional health and wellbeing. It supports us to foster a better relationship with ourselves and minimise stress and anxiety. It teaches us to be mindful of our own needs, to better support ourselves and others.

Find support & community
at monthly online catch-ups



By understanding, planning, and taking proactive steps, those living with hypersomnia can navigate their daily lives with more clarity and ease.



PO Box 5278, Algester QLD 4115



info@hypersomnolenceaustralia.org.au

HYPERSOMNOLENCE
AUSTRALIA

19662120036 **ABN**

hypersomnolenceaustralia.org.au 

DISCLAIMER - The content of this document is for support purposes only & does not substitute professional medical advice. Any health concerns should be discussed with a doctor.