Tips for Living with Hypersomnolence

HYPERSOMNOLENCE AUSTRALIA

Practical advice for everyday life, drawn from lived experience and informed by clinical understanding.

These tips are intended for people living with idiopathic hypersomnia or narcolepsy, and for the healthcare professionals who support them.

Waking up and getting going

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

For some people, having another person physically wake them is necessary. 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 helps me to get through the wake-up ordeal."
>
> **Michelle Chadwick**



Organise your morning the night before

Prepare as much as you can in advance, for example, kids' uniforms, lunches and bags before bed. Plan ahead, make lists and set reminders.

Tasks that might take most people an hour can take much longer when you live with idiopathic hypersomnia or narcolepsy. Being prepared can help to reduce stress and anxiety, and may help with task completion.

Managing your energy and self-care

Living with idiopathic hypersomnia or narcolepsy can be challenging, but there are things you can do to manage your energy, look after yourself and support your overall wellbeing.

Be kind to yourself and protect your energy

Quiet your inner critic and focus on accepting where you are. Celebrate your successes. Learn your strengths and limitations, then adjust your expectations accordingly. You know yourself and your limits better than anyone else; be clear and confident when sharing your needs and boundaries. Your time and energy are valuable, so it's ok to protect them and say no.

Identify when you're most productive

Notice when you have the most energy or focus, and plan key tasks for that time. 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.

Self-care

Practising 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 in order to better support ourselves and others.

Grief and Acceptance

It's normal to grieve the loss of who you were before your symptoms began, or who you hoped to be. Acceptance doesn't mean giving up; it means making peace with change so you can move forward.

Acceptance helps you appreciate when treatments work, and to create a life that fits your condition: one that's realistic, balanced and free of guilt or shame. Letting go of self-criticism allows you to set kinder goals and build a future that feels brighter and more your own.

Healthcare support, treatment and lifestyle

Find the right healthcare support

Surround yourself with the right healthcare team – people who listen, believe you and are willing to learn with you. This may include your GP, sleep specialist, occupational therapist, psychologist (for mental health support), nutritionist, or movement specialist. Having supportive professionals around you makes it easier to manage symptoms and talk openly about what is or isn't working.

Give yourself a break from medication

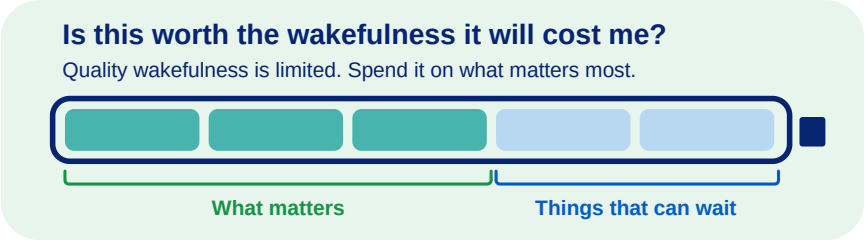
To help prevent tolerance, plan regular days off your wake-promoting medication, for example, weekends when you may not need to drive or make important decisions. Some people take a longer break, such as during holidays. If your medication feels less effective, these breaks may help to reset your tolerance.

Adequate sleep is very important

While it may be tempting to use medication to enable you to participate in life more, it is important to understand that people with idiopathic hypersomnia generally do not function well on less sleep than they're used to.

You might manage on an average person's 7-9 hours of sleep for a day or two, but pushing beyond that often leads to a crash. Many people who've learned to manage their symptoms still sleep excessively despite medication – they just sleep a little less excessively.

Prioritise sleep and build a routine that works for you. If naps help, as they often do for people with narcolepsy, schedule them. Pay attention to your sleep environment and notice how light, especially sunlight, affects your body clock. Good sleep hygiene and consistency can make a big difference.



Nourish your body and keep it moving

Good nutrition and hydration won't make idiopathic hypersomnia or narcolepsy disappear, but poor nutrition, dehydration, or vitamin and mineral deficiencies can make symptoms worse or more difficult to manage. That afternoon crash may not only be caused by the hypersomnia hitting you when your medication wears off, it can also be made worse by the carbohydrates (sugars) consumed earlier in the day.

Learn about the effects of dehydration and electrolyte imbalance. Prioritise physical activity just as you do sleep and nutrition. Living with idiopathic hypersomnia or narcolepsy often means being highly sedentary, which can negatively affect the body's musculoskeletal and cardiovascular systems, lower mood and reduce overall wellbeing.

Even small amounts of movement can help. Try gentle activities that feel achievable, such as a short walk, stretching at home, watering the garden or taking the dog out. The goal isn't traditional "exercise," but regular movement that supports circulation, muscle tone and mood in ways that fit your energy levels.

Learn more about the effects of dehydration and electrolyte imbalances.

Find community - You're not alone!

Community connection matters not only because of the practical information shared, but because there can be immense relief in being around people who understand without needing to explain.

Hypersomnolence Australia's Living with Idiopathic Hypersomnia and Living with Narcolepsy community groups bring people together to share conversation, connection and lived experience. These friendly groups provide a space to discuss daily challenges, exchange ideas and learn how others navigate life with their condition.

Guided by experienced facilitators, the groups provide a comfortable environment where everyone can participate, listen and feel part of a community.

More information about our community groups

About Us: Hypersomnolence Australia is a registered not-for-profit health promotion charity dedicated to advocacy, awareness, education, and research to improve outcomes for people living with Idiopathic Hypersomnia & Narcolepsy

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