

# TIPS FOR LIVING WITH HYPERSONMIA

Practical advice for people living with idiopathic hypersomnia or narcolepsy, and for the healthcare professionals who support them.

*These tips are drawn from lived experience, and informed by clinical understanding.*

## **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.



## **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 to talk openly about what is or isn't working.

## **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.

## **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 reset your tolerance.

## **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.

## **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 an hour for others can take much longer when you live with idiopathic hypersomnia or narcolepsy. Feeling prepared helps reduce stress and anxiety.

## **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.

## 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 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.

## Adequate sleep is essential.

While it may be tempting to use medication to enable you to participate in life more, it's 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 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 (sugar) you've eaten 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, 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.*

## You're not alone — join our community

Hypersomnolence Australia provides opportunities for people living with idiopathic hypersomnia and narcolepsy to connect through our online Living with... Community Groups. These groups offer a friendly, safe space to share experiences and challenges, and engage with others who truly understand. Facilitated by experienced members of our team, these regular catch ups help reduce isolation and provide reliable information and a sense of community. Find for more information about our community groups [here](#).

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



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