

# Top 12 Tips for Living with Idiopathic Hypersomnia

*Practical advice for Patients, Carers, and treating Doctors.*



1. **“What can I do to help me get going in the morning?”**, is one of the most common questions I’m asked. Many people need someone to physically wake them, and I can certainly relate to that. Regardless, I still need to follow a particular routine.



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.

2. **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.
3. **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.
4. **Organise your morning the night before**, as much as possible. Eg; Prepare your kids’ uniforms, school bags and lunches, before you go to bed.
5. **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. Make lists and set reminders. Feeling prepared reduces anxiety.
6. **Know yourself and your limits.** You know more about yourself and your limits than a doctor does. Find a medical professional who actively listens and communicates well. Set boundaries and stick to them.
7. **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. Most people with Idiopathic Hypersomnia never feel fully awake. Medication can 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.
8. **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. 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 well still sleep excessively despite medication; they just sleep a little less excessively.

9. **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.
10. **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.
11. **Sleep Hygiene.** Your sleep environment and routines impact your sleep health. Prioritise sleep. Find a routine that works best for you, then stick to it. 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.
12. **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, to better support ourselves and others.

