

# DIAGNOSIS TO AFTERCARE

## Practical advice for treating doctors of patients with Narcolepsy & Idiopathic Hypersomnia

### Discussing the Diagnosis

The relief individuals may experience when diagnosed with idiopathic hypersomnia or narcolepsy, the confirmation that they have a genuine disorder, is often short-lived. Prepare your patient for this and help them to manage their expectations.

It is essential to recognise and acknowledge the profound impact a diagnosis of idiopathic hypersomnia or narcolepsy can have on individuals' lives. For many, grieving their health after a new medical diagnosis can be an unexpected challenge. The type of grief that comes with chronic illness is complex, and the cycle can restart with each new issue that arises. Some individuals may not even realise they are undergoing a grieving process. As healthcare providers, it is important to discuss potential consequences such as the need to reassess career options, adjust personal aspirations, or manage the effects on existing familial responsibilities. Displaying empathy and understanding towards these challenges is crucial.

Offer support to patients as they face challenges related to their disorder's impact on various aspects of life such as work, studies, family planning, and relationships. Assist them in finding strategies to manage these challenges effectively.

### Treatment

It is important to keep in mind that due to the range of different symptoms, severity, and additional complexities and comorbidities associated with narcolepsy and idiopathic hypersomnia, there is no 'one size fits all' approach to treatment. Finding a treatment plan that effectively addresses symptoms can present challenges. While certain therapies may work well for some individuals, others may experience limited benefits, continue to struggle, or experience side effects that outweigh the benefits.

### Medication

Provide honest information about the medications available in Australia and the reason why treatments that are available elsewhere in the world are not available here (if you don't know why, find out). Be clear about expectations, limitations and side-effects. Discuss optimal medication timing including interactions with food and caffeine (dexamphetamine) as well as interactions with other medications, including birth control (eg: modafinil/armodafinil). Remember, the medication that is available in Australia is designed to help manage some of the symptoms, it's not intended to eliminate them entirely. Stimulant medication including modafinil has the potential to make symptoms worse by depriving people of sleep. Clarify that medication does not replace the need for excessive sleep in those with idiopathic hypersomnia. If they have narcolepsy, chances are they are already sleep deprived so they may need to schedule naps.

### Cognitive Dysfunction

Individuals with idiopathic hypersomnia and narcolepsy often experience significant difficulties that impact their cognitive processes and executive function. Many people don't realise that the dysfunction they experience is related to their sleep disorder. This can cause confusion and distress and may even lead them to think they have something else 'wrong' with them. It would be helpful to initiate a conversation with your patient on this topic and explain that these symptoms are not uncommon, provide reassurance and offer practical advice on effectively managing these symptoms and challenges.

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## Laws & Safety

Discuss the implications of their condition and treatment on driving, operating machinery, and reporting obligations according to local laws and regulations. Help patients navigate the potential safety concerns related to their disorder and its impact on their ability to drive or work safely.

## Comorbidities

Acknowledge and validate the impact of chronic stress, depression, and anxiety on managing idiopathic hypersomnia and narcolepsy symptoms. Work collaboratively with patients to provide support in addressing these mental health aspects.

Emphasise the importance of a holistic approach to managing idiopathic hypersomnia and narcolepsy. Discuss a care plan with your patient. Explain to them what it is and how it can help them.

## Living with Idiopathic Hypersomnia & Narcolepsy Community Groups

Your support may encompass a range of valuable resources and strategies to assist patients on their journey. These may comprise follow-up appointments, referrals to qualified professionals such as counsellors, psychologists, or other allied healthcare providers, informative fact sheets, credible online resources, and patient support groups. Encourage patients to actively participate in their own education and self-help initiatives, empowering them to gain knowledge and navigate their condition effectively.

Hypersomnolence Australia believes in providing quality support to individuals living with idiopathic hypersomnia and narcolepsy, and our community support groups are a great way to do this. Our groups are a friendly, safe environment where members can discuss their challenges and successes as well as share advice, resources, and support. The groups are facilitated by experienced members of the Hypersomnolence Australia team and are designed to reduce social isolation and to provide support and information for people living with idiopathic hypersomnia and narcolepsy. Some of the topics discussed include, 'How to advocate for yourself', 'Pregnancy and Parenthood', and 'Ask a 'longtimer'. We often circle back to this last topic, as it is a great opportunity for those who are new to their diagnosis, as well as parents of young people with narcolepsy or idiopathic hypersomnia, to gain valuable insight from people further along in their journey. In order to accommodate a wider audience our meetings are held online on a monthly basis.

We also periodically hold 'special presentations' where we invite health professionals to give a presentation prior to our group meeting. During these presentations, experts in their field provide valuable information on topics such as cognitive behavioural therapy for health (CBT-H) and the importance of good nutrition and keeping active. This allows members to gain a better understanding of their condition and how to manage it more effectively, in a holistic way.

**Please tell your Narcolepsy and Idiopathic Hypersomnia patients about our Living with ... community groups!**

More information about our community groups



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



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