

FROM DIAGNOSIS TO AFTERCARE

Guidance for Health Professionals supporting individuals with Narcolepsy and Idiopathic Hypersomnia

The relief individuals may experience when diagnosed with narcolepsy and idiopathic hypersomnia, the confirmation that they have a genuine disorder, is often short-lived. This document aims to guide health professionals in helping individuals prepare for this adjustment and support them in managing their expectations.

Discussing the Diagnosis

It is essential to recognise the profound psychosocial impact narcolepsy and idiopathic hypersomnia can have on a person's life. Many experience a form of grief associated with chronic illness - a complex process that may resurface with each new challenge. Individuals may not always recognise this as grief, but rather as frustration, anger, or hopelessness. As healthcare providers, it is important to discuss potential implications, such as the need to reassess career goals, adjust personal aspirations, or manage changes to family and social roles. Showing genuine empathy and understanding in response to these challenges is essential.

Support people in addressing the broader impacts of their disorder on daily functioning, including employment, education, family planning, and relationships. Proactively discuss how these areas may be affected and help identify practical strategies to adapt. Where appropriate, coordinate with other health professionals such as occupational therapists, psychologists, or social workers to ensure comprehensive care and continuity of support.

Acknowledging Diagnostic Uncertainty

Diagnosing narcolepsy and idiopathic hypersomnia is challenging. Current diagnostic tools and criteria have significant limitations and results should always be interpreted within this context. It is important that doctors communicate these limitations clearly at the time of diagnosis, acknowledging the evolving understanding of these disorders and the potential for diagnostic uncertainty. Being transparent about diagnostic uncertainty helps build trust, manage expectations, and reduce potential harm if a diagnosis is later revised or withdrawn.

When a diagnosis is changed or withdrawn, the emotional impact can be significant. Many people feel confused, embarrassed, or even ashamed because they have shared their diagnosis publicly - sometimes within their communities, workplaces, or support networks. Doctors should consider engaging mental health professionals to help individuals process these feelings, accept the change, and adjust to the uncertainty that can follow. Compassionate guidance can make a substantial difference to a person's wellbeing and confidence.

Treatment and Medication Management

Because symptoms, severity, and comorbidities vary widely among people living with narcolepsy and idiopathic hypersomnia, treatment must be individualised. There is no single approach that suits everyone. Developing an effective plan can be challenging. Some individuals respond well to certain medications, while others experience limited benefit or side effects that outweigh the advantages. Provide clear and honest information about available therapies, including why some medications may not be accessible in Australia. Discuss realistic expectations, limitations, and potential side effects.

Clearly explain optimal medication timing, including interactions with food and caffeine (dexamphetamine), as well as interactions with other medications, including birth control (e.g. modafinil/armodafinil). Emphasise that medication aims to manage symptoms, not eliminate them entirely. Stimulants and wake-promoting agents have the potential to make symptoms worse by depriving people of sleep. Clarify that medication does not replace the need for excessive sleep in idiopathic hypersomnia. For those living with narcolepsy, chances are they are already sleep deprived - encourage scheduled naps to reduce sleep pressure and improve daytime functioning.

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Cognitive Dysfunction

Individuals living with narcolepsy and idiopathic hypersomnia often experience significant cognitive difficulties, including impairments in attention, memory, and executive function. Many do not realise that the dysfunction they experience - such as mental fog, slowed processing, or difficulty focusing - is directly related to their sleep disorder. This can cause confusion and distress and may lead some to believe that something else is “wrong” with them. Initiate a conversation on this topic to explain that these symptoms are common, provide reassurance, and offer practical advice on managing these challenges.

It is also vital for doctors to recognise that people living with narcolepsy and idiopathic hypersomnia are often cognitively impaired when they attend medical appointments. Many experience brain fog, word-finding difficulty, and at times may still be in a state of sleep drunkenness or on the verge of sleep during consultations. Doctors need to understand that this impaired cognitive state can affect how people describe their experiences. What might sound vague or inconsistent is often the result of impaired alertness, not a lack of insight or reliability. It’s crucial that doctors do not inadvertently invalidate a person’s lived experience simply because it doesn’t align neatly with textbook definitions or their own expectations.

Laws & Safety

Discuss the implications of narcolepsy and idiopathic hypersomnia on driving, operating machinery, and other safety-critical activities. Explain local reporting requirements and fitness-to-drive obligations so individuals understand their responsibilities under the law. Provide clear guidance to help them navigate licensing assessments, workplace safety expectations, and the steps required if their condition or medication affects alertness. Encourage open discussion about risk management and support them in developing realistic strategies to stay safe while maintaining independence wherever possible.

Holistic and Mental Health Considerations

Acknowledge and validate the impact of chronic stress, depression, and anxiety on managing narcolepsy and idiopathic hypersomnia. Work collaboratively to ensure these mental health aspects are addressed as part of overall care.

Emphasise the importance of a holistic approach that considers psychological wellbeing, lifestyle factors, and physical health. Develop a care plan together - explain what this involves, how it can help, and how coordinated input from different healthcare professionals can improve outcomes.

Living with Idiopathic Hypersomnia & Narcolepsy Community Groups

Hypersomnolence Australia provides opportunities for people living with narcolepsy and idiopathic hypersomnia 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.

We also host special presentations featuring health professionals who share expertise on areas such as CBT-H, nutrition, and physical activity. These sessions promote a broader understanding of narcolepsy and idiopathic hypersomnia, and offer practical approaches to living well with these conditions.

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

More information about our community groups

