FROM DIAGNOSIS TO AFTERCARE

Guidance for Health Professionals supporting individuals with Narcolepsy and Idiopathic Hypersomnia

Receiving a diagnosis of narcolepsy or idiopathic hypersomnia may bring relief by confirming that the person has a genuine disorder. However, that relief 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

Recognise the profound psychosocial impact narcolepsy and idiopathic hypersomnia can have on a person's life. Many people experience grief associated with chronic illness—a complex process that may resurface with each new challenge. It may present as frustration, anger or hopelessness rather than recognisable grief. It is important to discuss potential implications, including the possibility that some people may need to reassess career goals, adjust personal aspirations, or manage changes to family and social roles. Respond with genuine empathy and understanding.

Support people in identifying the practical changes they may need after diagnosis. This might include reduced working hours, adjusted start times or working from home; exam accommodations or an individualised learning plan; or assistance with domestic demands through redistributed responsibilities, cleaning support or meal-preparation services. Where appropriate, coordinate with other health professionals such as an occupational therapist, psychologist or social worker.

Acknowledging Diagnostic Uncertainty

Diagnosing narcolepsy and idiopathic hypersomnia is challenging, and current diagnostic tools and criteria have significant limitations. Explain these limitations at diagnosis, including the evolving understanding of these disorders and the possibility of diagnostic uncertainty. Transparency builds trust, manages expectations and may reduce harm if a diagnosis is later revised or withdrawn.

When a diagnosis is changed or withdrawn, the emotional impact can be significant.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. Consider involving a mental health professional to help them process the change and adjust to ongoing uncertainty. 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 for dexamphetamine, and interactions with hormonal contraceptives and risks during pregnancy for modafinil and armodafinil. Discuss other treatments where relevant, including antidepressants used for cataplexy, sodium oxybate, pitolisant and emerging orexin receptor agonists. Explain their intended role, potential benefits and risks, monitoring requirements and accessibility in Australia. 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 eliminate the excessive need for sleep in idiopathic hypersomnia. People living with narcolepsy may already be sleep deprived; encourage scheduled naps to reduce sleep pressure and improve daytime functioning.

Cognitive Dysfunction

People living with narcolepsy or idiopathic hypersomnia often experience difficulties with attention, memory and executive function. Many do not realise that mental fog, slowed processing or difficulty focusing can be related to their sleep disorder. Explain that these difficulties are common and offer practical management advice.

Remember that people may be cognitively impaired during appointments by brain fog, word-finding difficulty, sleep drunkenness or imminent sleep. This can affect how clearly they describe their experiences. Responses that seem vague or inconsistent may reflect impaired alertness, not a lack of insight or reliability.

Laws & Safety

Discuss how narcolepsy and idiopathic hypersomnia affect driving, machinery use and other safety-critical activities. Explain local reporting and fitness-to-drive obligations, workplace safety expectations, and what to do if the condition or medication affects alertness. Support realistic risk-management strategies that preserve independence wherever possible.

Holistic and Mental Health Considerations

Recognise and validate how the impact of chronic stress, depression and anxiety can affect condition management. 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's Living with Idiopathic Hypersomnia and Living with Narcolepsy community groups offer conversation, connection, and shared lived experience. Experienced facilitators create a friendly environment where people can discuss daily challenges, exchange ideas, and hear how others navigate life with their condition.

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

Scan for more information about our community groups:

DARE-CDH

Australia & New Zealand's patient registry for people living with narcolepsy, idiopathic hypersomnia and other central disorders of hypersomnolence.

By joining DARE-CDH, your patients can help build the evidence needed to improve understanding, research, advocacy and care.

Scan to learn more or join DARE-CDH.

About Us: Hypersomnolence Australia is Australia's leading voice for people living with Idiopathic Hypersomnia and Narcolepsy. We are a registered not-for-profit health promotion charity dedicated to advocacy, awareness, education and research to improve outcomes for people affected by these disorders.

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