

Narcolepsy Type 1

Orexin deficiency, with cataplexy

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There are two types of narcolepsy: narcolepsy type 1 (NT1) and narcolepsy type 2 (NT2). People with NT2 do not have cataplexy and generally have normal orexin levels. NT2 is less well understood. Researchers believe that NT2 may represent more than one underlying condition. This factsheet focuses on NT1. [1,10]

What is Narcolepsy type 1?

Narcolepsy type 1 (NT1), sometimes called narcolepsy with cataplexy, is a chronic neurological sleep-wake disorder. NT1 is caused by the loss of specific nerve cells in the brain's hypothalamus that produce orexin (hypocretin), a chemical messenger essential for regulating wakefulness and REM sleep. This loss is believed to result from an autoimmune response in which the immune system mistakenly attacks the body's own orexin-producing cells. [1]

Genuine cataplexy is the characteristic feature that distinguishes NT1 from other central disorders of hypersomnolence. Cataplexy may not be obvious at first and can begin after other narcolepsy symptoms have developed. [1]

Symptoms of Narcolepsy type 1

- **Excessive daytime sleepiness:** A persistent struggle to remain awake, an irresistible need to sleep and unintended episodes of sleep during the day. Short naps are often refreshing, but the sleepiness returns. [1]
- **Cataplexy:** A sudden, involuntary loss of muscle tone or muscle control that occurs while a person is awake. It is triggered by strong emotion, most characteristically laughter, amusement, excitement, joking, and occasionally anger. The severity may vary. It can cause partial muscle weakness, such as the jaw sagging, the head dropping or the knees buckling. In rare cases, complete paralysis can affect the whole body. The person always remains conscious. [1,2]
- **Disturbed or fragmented nighttime sleep:** Repeated awakenings, vivid dreams and difficulty maintaining sleep are common. [1,3]
- **Sleep paralysis:** A temporary inability to move or speak when falling asleep or waking up. Episodes usually last from a few seconds to a few minutes. [1]
- **Sleep-related hallucinations:** Hypnagogic hallucinations occur while falling asleep, and hypnopompic hallucinations occur while waking up. These vivid sensory experiences may involve seeing, hearing or feeling something that is not present. They can be frightening or confusing. [1]

Cataplexy is not fainting or a sleep attack.

During cataplexy, the person remains awake and conscious. If you pass out, black out, lose consciousness or have unexplained episodes of weakness, falls or collapse, speak to your doctor so the cause can be investigated. See Hypersomnolence Australia's Identifying Genuine Cataplexy factsheet for a detailed explanation of cataplexy.

Narcolepsy type 1 in children and adolescents

In children, sleepiness may appear as irritability, hyperactivity, inattention, behavioural change or declining school performance. Rapid weight gain can occur around disease onset. Cataplexy may initially include facial slackening, drooping eyelids, repeated mouth opening, tongue protrusion, an unsteady gait or additional movements alongside loss of muscle tone. Assessment by a clinician familiar with paediatric narcolepsy is important. [4,5]

Diagnosis

Diagnosis begins with a detailed clinical history, including the pattern and onset of sleepiness, a careful description of possible cataplexy, nighttime sleep, sleep schedule, medications and other factors that may contribute to sleepiness. Information from someone who has witnessed cataplexy can be helpful.

An overnight sleep study, called polysomnography, is followed the next day by a Multiple Sleep Latency Test (MSLT). The MSLT measures how quickly a person falls asleep and whether REM sleep occurs soon after sleep onset. Results must be interpreted in the context of adequate prior sleep, medication effects and the full clinical picture. [1]

Measurement of orexin in cerebrospinal fluid can confirm NT1. This is particularly valuable when cataplexy is absent, has not yet developed or reported episodes are not clearly genuine cataplexy. [1]

Treatment and management

There is currently no cure for NT1. Treatment is individualised and may address daytime sleepiness, cataplexy and disrupted nighttime sleep separately. [6]

- **Daytime sleepiness:** Wake-promoting and stimulant medicines used in Australia include dexamphetamine, modafinil and armodafinil.
- **Sodium oxybate:** Can improve excessive daytime sleepiness, cataplexy and disrupted nighttime sleep. It was registered in Australia in July 2026 for narcolepsy in adults and in children and adolescents aged seven years and older. Access and subsidy arrangements should be discussed with the treating specialist. [8]
- **Cataplexy:** Some antidepressant medicines are prescribed to reduce cataplexy. [6]
- **Daily management:** Planned brief naps and a regular sleep–wake schedule may help manage symptoms. Improvement in general health and wellbeing through healthy sleep practices, nutrition, and fitness can help improve overall quality of life for people with narcolepsy.

Important information about modafinil and armodafinil

These medicines can reduce the effectiveness of hormonal contraception. The TGA also advises against using modafinil and armodafinil during pregnancy because these medicines are suspected to cause birth defects and miscarriage. Discuss contraception, pregnancy planning and medication safety with the prescribing doctor or pharmacist. [9]

Living with narcolepsy type 1

Living with narcolepsy type 1 can affect education, work, driving, relationships, independence and overall quality of life. Appropriate adjustments at school, university or work may be needed. Medication can improve symptoms, but it may not restore normal alertness or address every impact of the condition. Reliable information and connection with others who understand can help people live better with NT1. Hypersomnolence Australia's website provides practical information and resources, as well as opportunities to connect with the narcolepsy community through our Living with Narcolepsy Community Group. [6,7]

References

1. Bassetti CLA, Adamantidis A, Burdakov D, et al. Narcolepsy—clinical spectrum, aetiopathophysiology, diagnosis and treatment. *Nature Reviews Neurology*. 2019;15:519–539. [Link](#)
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3. Maski K, Mignot E, Plazzi G, et al. Disrupted nighttime sleep and sleep instability in narcolepsy. *Journal of Clinical Sleep Medicine*. 2022;18:289–304. [Link](#)
4. Maski K, Owens JA. Insomnia, parasomnias, and narcolepsy in children: clinical features, diagnosis, and management. *Lancet Neurology*. 2016;15:1170–1181. [Link](#)
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6. Bassetti CLA, Kallweit U, Vignatelli L, et al. European guideline and expert statements on the management of narcolepsy in adults and children. *European Journal of Neurology*. 2021;28:2815–2830. [Link](#)
7. Maski K, Steinhart E, Williams D, et al. Listening to the patient voice in narcolepsy: diagnostic delay, disease burden, and treatment efficacy. *Journal of Clinical Sleep Medicine*. 2017;13:419–425. [Link](#)
8. Therapeutic Goods Administration. Sodium Oxybate-Reach (sodium oxybate): Australian Prescription Medicine Decision Summary. 2026. [Link](#)
9. Therapeutic Goods Administration. Australian Product Information: MODAVIGIL (modafinil) and NUVIGIL (armodafinil). [Link](#)
10. Fronczek R, Arnulf I, Baumann CR, et al. To split or to lump? Classifying the central disorders of hypersomnolence. *Sleep*. 2020;43(8):zsaa044. [Link](#)

Hypersomnolence Australia resources

Visit the Hypersomnolence Australia Resources page for reliable information and practical guidance, including:

- Identifying Genuine Cataplexy
- Driving with Narcolepsy in Australia
- Know Your Workplace Rights
- Top Tips for Living with Hypersomnia
- Information about medications used in Australia

hypersomnolenceaustralia.org.au/resources

Living with Narcolepsy community group

Hypersomnolence Australia's Living with Narcolepsy community group brings people diagnosed with narcolepsy together to share conversation, connection and lived experience. The group meets online each month and is guided by an experienced facilitator.

[Learn more and register](#)

About Hypersomnolence Australia

Hypersomnolence Australia is a health promotion charity dedicated to driving awareness, education and research to improve outcomes for people living with Idiopathic Hypersomnia and Narcolepsy. HA receives no funding and charges no membership.

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Disclaimer: This factsheet is for information purposes only and is not a substitute for professional medical advice. Any concerns about your health should be discussed with your doctor.

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