

WHAT IS NARCOLEPSY?

Narcolepsy is a chronic and incurable neurological disorder that impairs the brain's ability to regulate the sleep-wake cycle.

Due to low awareness and misperceptions, it usually takes several years for people with narcolepsy to receive a diagnosis while even more are currently undiagnosed or misdiagnosed.

There are two types of Narcolepsy: narcolepsy with cataplexy (episodes of muscle weakness), and narcolepsy without cataplexy.

SYMPTOMS OF NARCOLEPSY

The main symptoms of narcolepsy with cataplexy are:

- excessive daytime sleepiness
- visual and auditory hallucinations
- sleep paralysis
- cataplexy (muscle weakness)
- disrupted night-time sleep

People with narcolepsy without cataplexy experience excessive daytime sleepiness.

For more information on these symptoms, go to: <https://www.sleepoz.org.au/narcolepsy>

DISCLAIMER: Information provided in this fact sheet is general in content and should not be seen as a substitute for professional medical advice. Concerns over sleep or other medical conditions should be discussed with your family doctor.

ABOUT US

Sleep Disorders Australia (SDA) is a voluntary Not-for Profit organisation that provides support and information as well as education regarding treatment, to people affected by sleep disorders throughout Australia. SDA advocates the needs of people with sleep disorders by raising awareness of sleep disorders and the impact they have on the lives of those living with them.

New members are always welcome. Our membership is available to anyone living with a sleep disorder, their family members, health care professionals, and any member of the public who has an interest in sleep disorders. You can join SDA via our website or email our membership officer for more information.

If you would like to support us with a financial donation, you can do so via our website or you can send a cheque to our address.

CONTACT INFO

-  www.sleepoz.org.au
-  admin@sleepoz.org.au
-  Sleep Disorders Australia
PO Box 5278 Algester Qld 4115
- FACEBOOK SUPPORT GROUP
www.facebook.com/groups/SDASupport
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A PATIENTS GUIDE TO LIVING WITH NARCOLEPSY



ONE STEP AT A TIME IS ENOUGH,
AS LONG AS THE STEP YOU TAKE
IS FORWARD. - Fiona



 Sleep
Disorders
Australia

TREATMENT FOR NARCOLEPSY

Finding the most effective treatment for you is an individual process and one that can take time. While treatment options are limited in Australia, your symptoms can be better managed with a combination of prescribed medications, daytime naps, and lifestyle changes. Narcolepsy is a lifelong condition and just as your body will change over a lifetime, your treatment will also need to change to remain effective.

CLOSING THE GAP BETWEEN OPINIONS AND FACTS ABOUT NARCOLEPSY CAN ONLY BE DONE BY LISTENING TO AND LEARNING FROM THOSE LIVING WITH IT.
- Fiona



NAVIGATING LIFE WITH NARCOLEPSY

N	Narcolepsy can affect many aspects of our lives, including our self-esteem, our social interactions, and our quality of life.
A	Adapting and adjusting to life with narcolepsy is challenging and takes time. A combination of treatment medications, lifestyle changes, regular exercise, daytime naps and maintaining a regular sleep schedule can help.
R	Routines can help with symptom management, but adhering to them requires discipline, because to do so reduces our availability to others which can create feelings of guilt. Following a routine does not make us selfish, lazy, needy, or controlling. It makes us responsible and self-aware.
C	Cognitive impairment (brain fog) is often experienced by people with narcolepsy and can make it difficult to concentrate on tasks or conversations for too long, retain information, make decisions, and communicate our thoughts. Taking regular breaks, setting reminders, and writing things down can help.
O	Our mental and emotional well-being can be impacted by narcolepsy as well. For some, coming to terms with a life-altering and incurable medical condition means going through a grieving process. There's no timeline, it's different for everyone, and there are no right or wrong feelings.
L	Listen to your body and you will learn what triggers your symptoms and/or makes them worse. This knowledge and insight will help you find coping mechanisms that work for you.
E	Educate family, friends and loved ones on how narcolepsy impacts your life and how best they can support you, keeping in mind that their lives will be impacted as well.
P	Peer support and connecting with others via social media and online support groups can help you adjust and feel less isolated.
S	Side effects of medications are often overlooked, however it's important to be aware of them. Any concerns you have should be discussed with your treating health practitioner as soon as possible.
Y	you will find some days harder than others and that's okay. We all do. It takes courage and determination to live life with narcolepsy. Remember that. You are strong. Narcolepsy strong!

REACH OUT FOR SUPPORT. YOU DON'T HAVE TO WALK ALONE.

Initiating, implementing, and maintaining long-term lifestyle changes for people with narcolepsy can be difficult. A holistic approach that considers your mental and social wellbeing as well as the symptoms is both important and necessary. Support and validation by peers who understand can also help you feel less alone and isolated.

Sleep Disorders Australia runs a regular Living with Narcolepsy online support group where you can share your experiences with others who can relate. For further information on narcolepsy and how you can join our LWN Support Group please go to the narcolepsy page on SDA's website www.sleepoz.org.au/narcolepsy