



FALLING ASLEEP

A Narcolepsy Guidebook

Designed by Eleanor Wales

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Contents:

Introduction	1
What is Narcolepsy?	3
Who Gets Narcolepsy?	7
Symptoms of Narcolepsy	11
Why Narcolepsy Occurs	17
Understanding Sleep Cycles	21
Treating Narcolepsy	29
Emotional Impacts	35
Living With Narcolepsy	43
More Information	52
Publication Details	53
Bibliography	54

INTRODUCTION

ARE YOU OFTEN VERY SLEEPY DURING THE DAY?

DO YOU SOMETIMES FALL ASLEEP BY ACCIDENT?

IS YOUR NIGHTTIME SLEEP DISRUPTED OR NOT RESTFUL?

DO YOU WAKE UP FEELING UNREFRESHED?

You are not alone.

As a narcoleptic, you have a sleep-wake disorder that can affect you 24 hours a day. There is no cure for Narcolepsy, but with proper care its symptoms can be reduced.

This book provides insight into this often misunderstood condition for Narcoleptics themselves, as well as acting as a tool to help you explain your condition to others.



What is Narcolepsy?

Narcolepsy is a serious, life-long neurological disorder that can affect all areas of a person's life.

Depending on the severity of symptoms, it can cause tremendous strain on relationships with family and friends, affect education and employment, make driving and outings hazardous, and even turn small daily tasks into major chores.



WHY IS NARCOLEPSY A PROBLEM?

Many people don't understand Narcolepsy. Some may think your sleepiness is due to laziness or lack of attention. Others may not see falling asleep during the day as a serious problem.

DESPITE SUCH IGNORANT ATTITUDES, NARCOLEPSY IS A SERIOUS MEDICAL DISORDER THAT CAN AFFECT A PERSON'S LIFE IN MANY WAYS.

Narcolepsy can keep you from getting the nighttime sleep your body needs to stay healthy. It can cause emotional and social difficulties. It can put your job or education at risk. And it can lead to mistakes and accidents that can endanger your health and even your life. So it is important to get proper treatment.

Who Gets Narcolepsy?

Narcolepsy patients do not fit any specific profile. The disorder is found in all types of people around the world, affecting an equal number of male & female patients.

HOW MANY PEOPLE HAVE IT?

In Australia, about 1 in 2000 or 0.05% of people have narcolepsy. However, many of these people may not be aware that they have it.

Narcolepsy is about as common as multiple sclerosis and Parkinson's Disease. You hear less about it because it is so misunderstood.

IS IT HEREDITARY?

Although there is a genetic component to narcolepsy, most narcolepsy patients have no known relative with the disorder. Research has found that if a person has certain genes, they are more likely to have narcolepsy. However, having these genes does not always mean that narcolepsy will result.

WHEN DOES IT APPEAR?

In most cases, narcolepsy symptoms first appear when patients are between the age of 10 and 25, but they can appear at any age and in any order.

Many patients find that symptoms get worse as they get older. Other patients find that symptoms lessen over time, although they never go away completely.



Symptoms of Narcolepsy

?

DAYTIME SYMPTOMS

- **Excessive daytime sleepiness (EDS)** affects 100 percent of narcolepsy patients. With EDS, patients feel abnormally sleepy at different times throughout the day. They may also fall asleep quickly and at inappropriate times, such as while eating or talking. These unplanned sleep episodes are called “sleep attacks.”
- **Cataplexy** affects 60 to 100 percent of narcolepsy patients. It involves sudden loss of muscle tone or strength. It can result in drooping eyelids and face, buckling of the knees, or paralysis of the whole body. Cataplexy attacks usually last less than 30 seconds. They are mostly triggered by laughter or sudden feelings of anger, fear, or surprise.
- **Automatic behaviour** involves patients seeming to “fall asleep” while they are awake. They may perform routine tasks and not remember them afterward. They may also jump from topic to topic while speaking, or suddenly stop talking in the middle of a discussion.



CATAPLEXY

NIGHTTIME SYMPTOMS

- **DISRUPTED NIGHT-TIME SLEEP (DNS)** affects 60 to 90 percent of narcolepsy patients. It is due to patients' irregular sleep cycles. Patients wake up often throughout the night, and can have trouble getting back to sleep. DNS can prevent patients from getting enough sleep, and can worsen EDS.
- **SLEEP PARALYSIS** occurs in about 60 percent of narcolepsy patients. It usually occurs when the patient is falling asleep or waking up. The person is conscious but cannot move or speak. Episodes can last a few seconds or several minutes. They can cause panic in a patient if he or she is not familiar with this symptom.
- **HYPNOGOGIC HALLUCINATIONS** affect up to 66 percent of narcolepsy patients. They are vivid, often frightening dreams that happen when the patient is falling asleep or waking up. They can involve images, sounds, touch, smell, may seem very real, and can often occur at the same time as sleep paralysis.



HYPNOGOGIC HALLUCINATION

IT IS THOUGHT THAT NARCOLEPSY IS CAUSED BY THE BODY'S IMMUNE
SYSTEM DESTROYING HYPOCRETIN-PRODUCING CELLS IN THE BRAIN

Causes of Narcolepsy

The past two decades have seen a significant increase in the number of scientific studies of narcolepsy, and advances in this time have concluded that it is caused by problems with our brain chemistry.

LACK OF HYPOCRETINS

These are chemicals produced in the brain that are involved with several brain functions, including the sleep-wake cycle. They help a person wake up and stay awake.

- **WHY ARE HYPOCRETINS LACKING?** Studies have shown that low hypocretin levels are caused by the loss of brain cells that produce these chemicals. Some scientists think that an autoimmune reaction is involved, where a person's immune system attacks the body itself instead of an outside invader. In this case, the immune system of narcolepsy patients mistakenly attack the cells in the brain that produce hypocretins.
- **WHAT IS TRIGGERING THE PROBLEM?** The specific trigger or triggers that cause the autoimmune response are not yet known. Possible triggers include viruses, exposure to toxins, accidents, stress, drug use, abrupt changes in sleep patterns, and hormonal changes.



AWAKE

DROWSY

STAGE 1

STAGE 2

DELTA SLEEP

REM SLEEP

Understanding Sleep Cycles

Everybody goes through certain stages during sleep. However, the timing and order of these different stages vary greatly between healthy and narcoleptic people when they sleep.

HEALTHY SLEEPERS

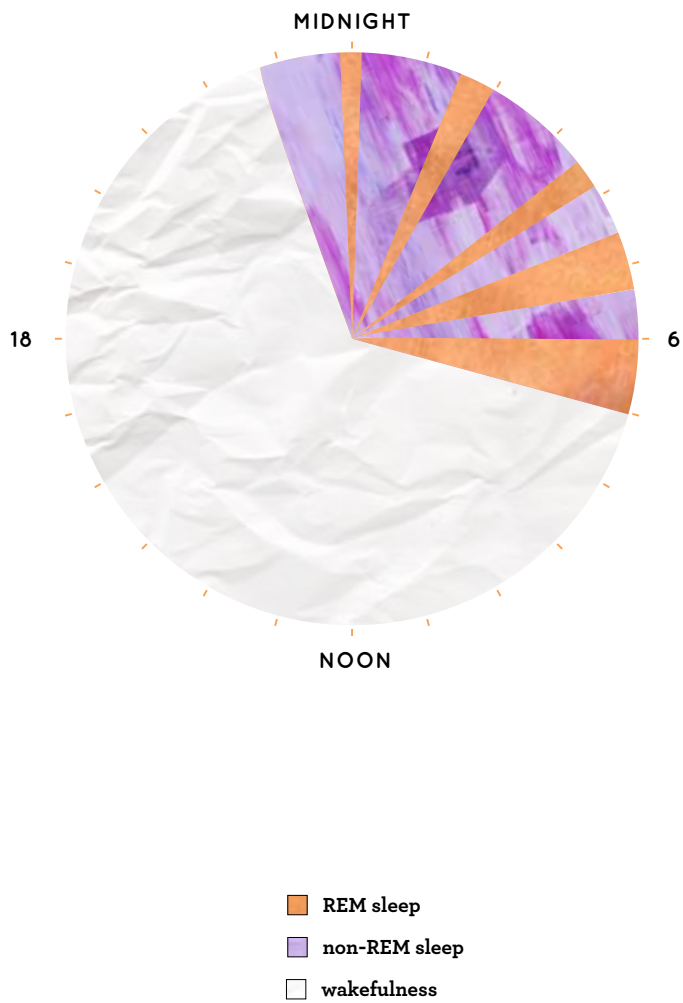
Healthy sleepers usually sleep between six and eight hours during each night (on average).

While sleeping, they go through several stages. Stages 1 and 2 consist of lighter sleep (thought to restore the body's energy and immune system). These four stages are known as non-REM (rapid eye movement) sleep, or quiet sleep.

Brain waves slow down during non-REM sleep. Then, after about 90 minutes, the sleeper enters REM, or "active", sleep. It is during this stage that brain waves speed up, as this is when dreams occur, and muscles are paralysed (believed to have evolved to keep sleepers from acting out their dreams).

Sleepers may cycle through each one of these sleep stages 4 or 5 times every night.

The graphic opposite illustrates a normal sleeper's regular sleep-wake cycle during a 24-hour period.



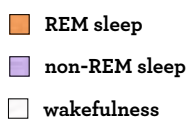
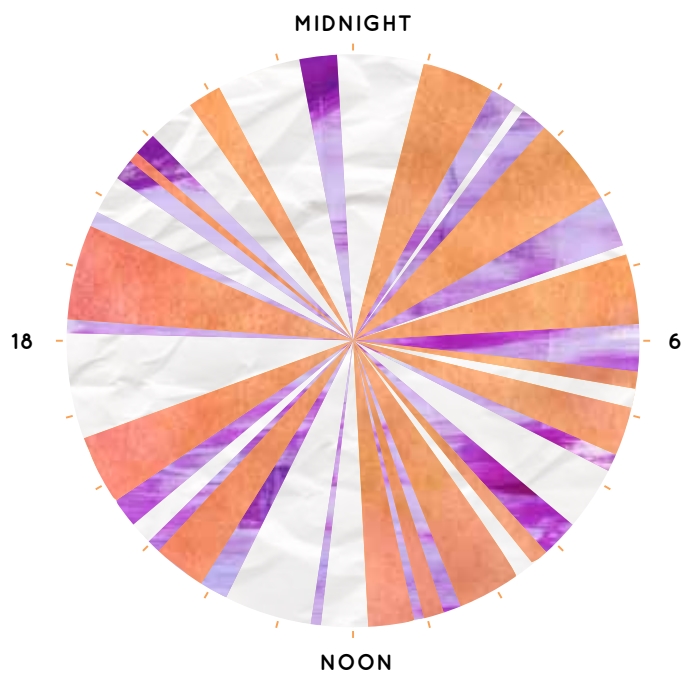
NARCOLEPTIC SLEEPERS

Narcoleptic sleepers typically do not get 6 to 8 hours of sleep all at once. Instead, their sleep cycle is spread out over all 24 hours of the day.

They may sleep a normal amount each day in total, but cannot control the timing of their sleep. Often, they get only brief periods of sleep during the night. It is because of this lack of night-time sleep that they need to make up the rest during the day, which can result in excessive sleepiness and sleep attacks.

The length and order of sleep stages are also different for narcoleptic sleepers. Stage 1 sleep is increased, with stages 3 & 4 greatly decreased. Upon falling asleep, narcoleptics enter REM sleep almost straight away. This is known as a Sleep Onset REM Period (SOREMP). These SOREMPs are often brief. Because of these abnormal sleep patterns, narcoleptic sleepers rarely get enough of most stages of sleep, which may have negative impacts on their general health.

The graphic opposite illustrates a narcoleptic sleeper's irregular sleep-wake cycle during a 24-hour period.



WHY IS A HEALTHY SLEEP CYCLE IMPORTANT?

ADEQUATE SLEEP IS VITAL FOR EVERYONE.

Research shows that REM sleep may aid in memory, learning and mood regulation. Certain stages of non-REM sleep may help our bodies restore energy and repair damaged cells.

Researchers are still uncertain about the role of sleep in our overall functioning, however, they do know that not getting enough sleep can be harmful. Even healthy sleepers who get 1 or 2 fewer hours of sleep than usual show signs of physical and mental problems.

These can include:

- Decreased attention, poor mood and low energy
- Being prone to accidents and mistakes
- Impaired immune function
- Increased risk of heart disease and type 2 diabetes
- Reduced quality of life

So it's easy to see why getting the proper treatment for your Narcolepsy is important.



MEDICATIONS USED BY NARCOLEPTICS:
7% ANTI-CATAPLEXY ONLY

20% STIMULANT & ANTICATAPLEXY

24% UNMEDICATED

Treating Narcolepsy

Treatment for Narcolepsy usually consists of medication and behavioural changes.

MEDICATION

MOST LIKELY, YOUR TREATMENT WILL NOT RELIEVE ALL OF YOUR SYMPTOMS, and it may take weeks or months to find a combination of treatments that works for you.

However, the sooner you start working on a proper treatment plan, the sooner you can start to feel better and live a more normal life.

Talk to your doctor or sleep specialist about whether medication is a good choice for you. Effective prescription medications may significantly improve the multiple symptoms associated with Narcolepsy.

Common medications used in Australia include stimulants such as Dexamphetamine and Modafinil to keep you awake and alert during the day, while anti-depressant medications are often used to help avoid Cataplexy (with a limited impact on Hypnagogic Hallucinations and Sleep Paralysis).



BEHAVIOURAL CHANGES

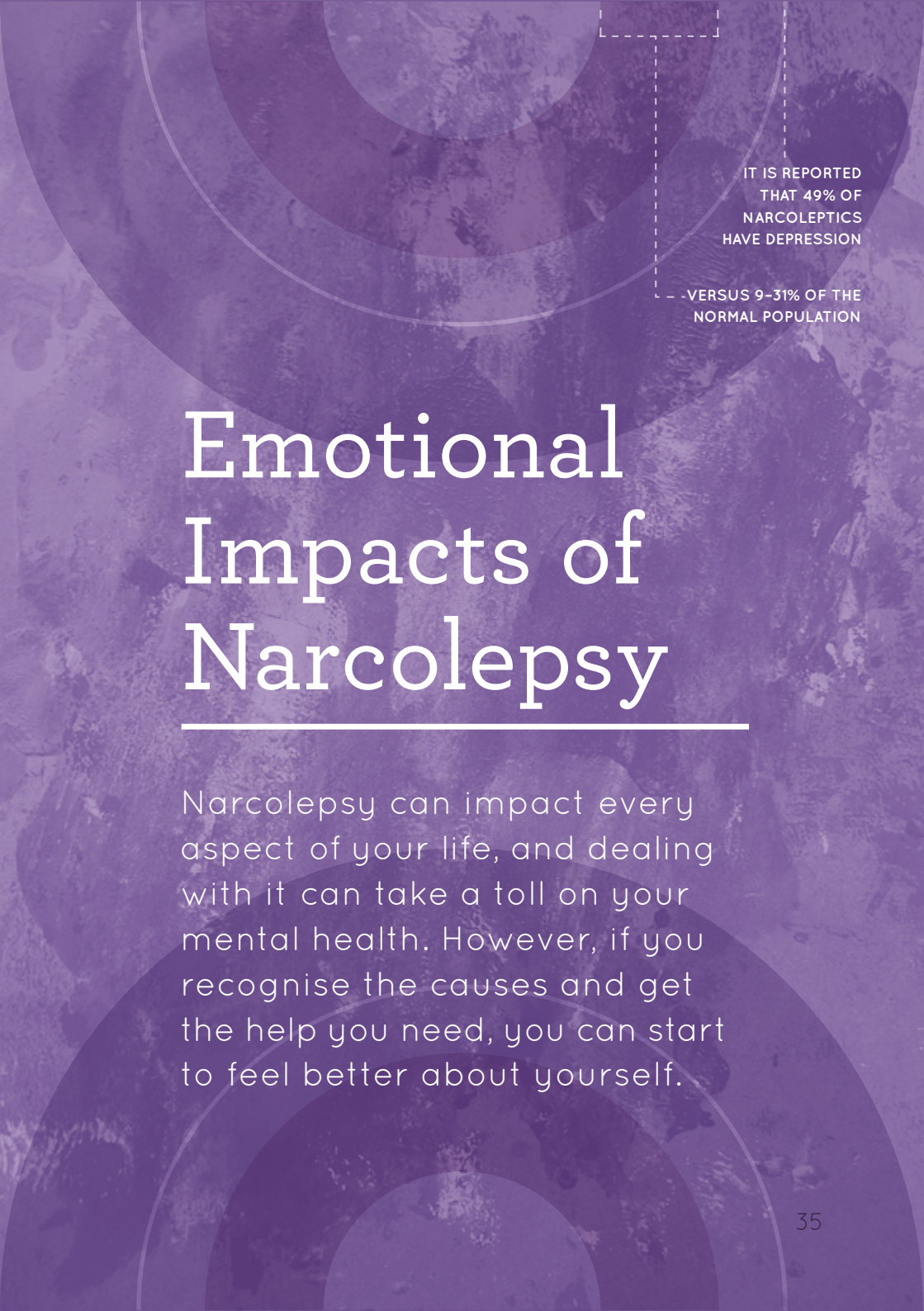
TO HELP MANAGE EDS AND DNS, IT IS IMPORTANT FOR NARCOLEPTICS TO PRACTICE HEALTHY SLEEP HABITS.

This idea is also known as **sleep hygiene**, which involves trying to use the right indicators to make it as obvious as possible to your brain when and where it is meant to be either asleep or awake.

Here are some tips that may help you to sleep better at night and be more alert during the day:

- **TRY DAILY NAPS.** Many narcolepsy patients benefit from naps of different kinds. Some take several short naps of 10-20 minutes each, while others find one long nap more helpful. In any case, make sure your naps do not interfere with your nighttime sleep.
- **GO TO BED AND GET UP AT THE SAME TIME EACH DAY.** Establishing a regular schedule helps your body to know when it is time to sleep.

- **USE BEDS FOR SLEEP & SEX ONLY.** This helps create more of a barrier between sleep and wake, associating the bed with sleep time.
- **RELAX BEFORE BEDTIME.** Take a warm bath, practice yoga, or meditate. This can help signal to your body that it's time to settle down and sleep.
- **AVOID CAFFEINE, ALCOHOL AND NICOTINE LATE IN THE DAY.** These substances can keep you awake at night-time.
- **AVOID BRIGHT LIGHTS IN THE HOUR BEFORE BED.** Bright lights e.g. those found in computer or television screens can interfere with your natural "body clock," making it harder to fall asleep.
- **EXERCISE REGULARLY.** It may help you feel more alert during the day and sleep better at night. Avoid strenuous exercise before bed.




IT IS REPORTED
THAT 49% OF
NARCOLEPTICS
HAVE DEPRESSION

— VERSUS 9–31% OF THE
NORMAL POPULATION

Emotional Impacts of Narcolepsy

Narcolepsy can impact every aspect of your life, and dealing with it can take a toll on your mental health. However, if you recognise the causes and get the help you need, you can start to feel better about yourself.



"...IT'S A BIT USELESS TRYING
TO EXPLAIN BECAUSE THEY DON'T
HEAR YOU OR WANT TO HEAR YOU,
**THEY THINK YOU'RE MAKING
A FUSS ABOUT NOTHING
ACTUALLY."**

THE PROBLEMS

Emotional problems affect many narcoleptic people, so if you have been faced with such an issue, it is helpful to remember that you are not alone and are simply experiencing a common symptom of the disorder.

COMMON PROBLEMS INCLUDE:

- **ISOLATION.**

Narcolepsy may cause you to withdraw from others emotionally. You may avoid other people because they don't understand your condition, or because you are embarrassed by your symptoms. You may also keep to yourself in order to avoid strong emotions, which can cause cataplexy attacks.

- **LOW SELF-ESTEEM.**

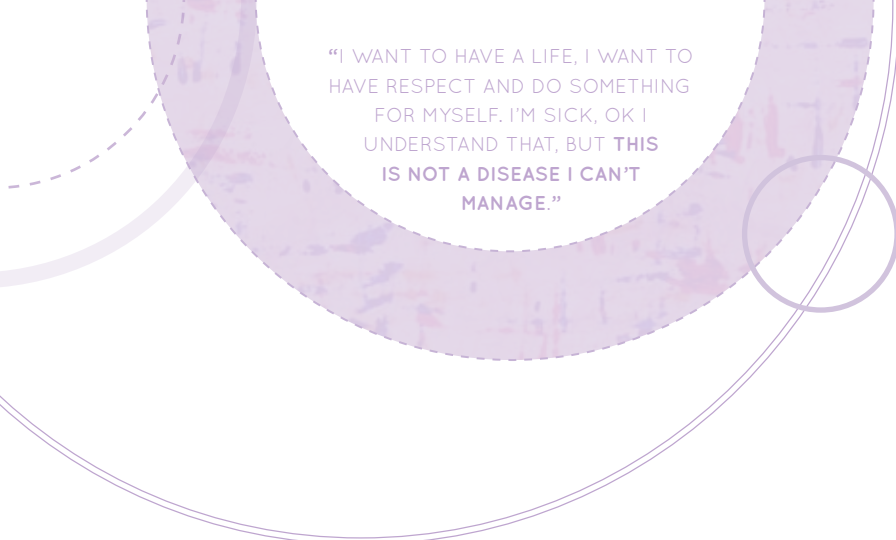
Having trouble functioning in your daily life can cause you to doubt yourself and your abilities. Your self-esteem can also suffer from others mistaking your symptoms for laziness or lack of discipline.

- **DEPRESSION.**

This condition can manifest itself from the negative emotions and isolation often caused by narcolepsy. Common symptoms include feeling down most of the time, losing pleasure in things that you used to enjoy, and having trouble focusing, remembering and making decisions.

- **SEXUAL PROBLEMS.**

Narcolepsy and some of the medications taken for it can cause low sex drive and impotence. Patients may even fall asleep during sex. These issues can be hard for your partner to understand, and may lead to an avoidance of physical intimacy.



"I WANT TO HAVE A LIFE, I WANT TO
HAVE RESPECT AND DO SOMETHING
FOR MYSELF. I'M SICK, OK I
UNDERSTAND THAT, BUT **THIS**
IS NOT A DISEASE I CAN'T
MANAGE."

COPING STRATEGIES

If you have any of the aforementioned problems, your first course of action should be talking to your doctor. Be sure to discuss any emotional issues as well as any related physical problems.

YOUR DOCTOR CAN HELP FIND WAYS OF COPING WITH YOUR CONDITION, SUCH AS:

- **SHARING WITH OTHERS.** Talk about your disorder with your family, friends, healthcare providers, even your neighbours. Talking about it can help others understand what narcolepsy is and what you're dealing with, as well as how they can help if needed.
- **SEEKING COUNSELLING.** Individual counselling can give you insight into your emotions, new tools for coping with problems and emotional support outside your usual network. Family and marriage counselling may also be of help, aiding you and those closest to you in working together to live more comfortably with your condition.
- **DEALING WITH DEPRESSION.** Depression is a serious illness. If you are diagnosed with it, your doctor may suggest medication or therapy. They may also give you tips on how you can try to feel better such as spending time with others, exercising and eating well, and taking life one day at a time.
- **JOINING A SUPPORT GROUP OR ORGANISATION.** In a support group, you can compare experiences and share coping strategies with others who have your condition. Here you can find a sense of empathy and understanding that may be hard to find elsewhere. Most importantly, you'll be reminded that you aren't the only person dealing with narcolepsy. There are even online groups where you can talk with other narcoleptics all over the world.*

*For some ideas of where to find a group, see the list on page 52.

TIPS FOR FAMILY & FRIENDS

The life of a person with narcolepsy isn't easy.

If you have a family member or friend with Narcolepsy, here are some ways that you can try to help:

- **LEARN** all you can about narcolepsy. A good knowledge of the condition can help you to better understand what your loved one is going through.
- **SUPPORT** your loved one and let them know you want to help. You could visit a support group together, or offer them with a lift when they can't drive.
- **LISTEN** to your loved one. Try not to judge, and don't attempt to comfort them with false promises or ways to "cure" their condition. Sometimes it helps just to be able to talk to someone.



"PEOPLE DON'T WANT YOU TO
FEEL BAD AND THEY TEND TO GO,
'OH I'M LIKE THAT TOO'.
BUT THEY'RE NOT LIKE IT TO
THE EXTENT THAT WE ARE."

Living with Narcolepsy

Narcolepsy can affect your life at work, at school and of course at home. The following ideas can help you understand and face challenges in order to live well with your condition.

WORKING

Without treatment, people with narcolepsy can have trouble performing their work duties, or even holding down a job at all.

However, with proper treatment, most can have a successful career in almost any field. Here are some tips:

- **FIND WORK THAT WORKS FOR YOU.** Avoid jobs that involve shift work, irregular schedules, long commutes, and lots of driving. Look for jobs that keep you busy, let you work with others, and allow a flexible schedule.
- **KNOW YOUR RIGHTS.** The **Australian Disability Discrimination Act (1992)** states that most employers should reasonably accommodate your condition. Such measures could include being allowed to take short naps, change your work schedule or modify your duties.



NARCOLEPTIC PEOPLE FEEL AS TIRED AS OTHERS WOULD FEEL
AFTER BEING DEPRIVED OF SLEEP FOR 48-72 HOURS STRAIGHT

LEARNING

Students with narcolepsy can have problems with memory and attention. These can result in learning or developmental difficulties, which can make schooling difficult.

- **FOR CHILDREN IN GRADES K-12:** Parents should tell teachers and school nurses about the condition and medications the child is taking.
- **FOR UNIVERSITY OR TAFE STUDENTS:** Tell your instructors about your condition to encourage understanding if you experience symptoms in class. Seek out services available to disabled students. If possible, nap before classes and avoid taking classes that run through the sleepiest part of your day. Also, try to choose small classes and study in a group to help retain knowledge.

The **Australian Disability Act** also includes standards state that any educational institution is required to make reasonable accomodations for students with any disability. The main aim of the Education Standards is to give students with a disability the right to participate in educational programs on the same basis as students without a disability.



IN ONE STUDY, OVER 50% OF RESPONDENTS SAID THEIR
NARCOLEPSY HAD CAUSED DIFFICULTY CONCENTRATING IN CLASS

STAYING SAFE

As people with narcolepsy may suddenly lose physical control at any time, safety should always be a consideration.

- **ACCIDENTS.** Sudden sleep episodes or cataplexy attacks can cause serious accidents. Even activities like cooking or walking down a flight of stairs can be dangerous if symptoms occur.

Make sure you get proper treatment for all of your symptoms, and avoid risky situations such as climbing ladders until your symptoms are under control.

- **DRIVING.** Fatigue is a contributory cause of 20-30% of all deaths on Australian roads, contributing as much as to the toll as speeding and drink driving, however, people who are treating their narcolepsy with medication have the same accident rate as other drivers.

While specific laws vary from state to state, usually narcoleptics can legally drive if they inform the appropriate authorities, complete a periodical medical review and are being treated for their EDS and cataplexy (if applicable). If you choose to continue driving, pay close attention to your level of alertness. Do not drive while drowsy. If you do become drowsy while driving, find a safe place to pull over and take a short nap.

MAINTAINING A HEALTHY WEIGHT

Many people with narcolepsy have problems with being overweight. This may be caused in part by a low activity level due to excessive sleepiness. It may also have to do with changes in brain chemistry that affect eating habits and metabolism.

No matter what the cause, it is important for people with narcolepsy to be mindful of this predisposition to weight gain, as being overweight can have many serious detrimental health effects if ignored for too long.

You can help to manage your weight and improve your overall health with:

- **EXERCISE.** Try to exercise regularly, as it can help improve alertness. It can also help curb your appetite and control weight gain.
- **PROPER DIET.** Eat lots of fruits, vegetables & whole grains, and limit processed foods. Eating a variety of nutritious foods can help you avoid weight gain, help prevent illness, and make you feel better. Keep in mind that foods with a high sugar or carbohydrate content can cause sleepiness. Limiting carbohydrates until the evening may help to improve daytime wakefulness.

A Healthy, Fulfilling Life

Narcolepsy is a serious, round-the-clock sleep-wake disorder that can have an enormous effect on your physical and mental health. But it can be managed.

Learn as much as possible about your condition, as with a little knowledge, some behaviour changes, and medication, you can live a healthier and more normal life.

More Information

For more information or support for Narcolepsy, please see the following useful sources:

Narcolepsy Network

WWW.NARCOLEPSYNETWORK.ORG

An international organisation, here you can find a good source of basic information on Narcolepsy as well as helpful educational booklets and one of the more popular global Narcolepsy discussion boards.

NODSS

(03) 9761-9767

WWW.NODSS.ORG.AU

The Narcolepsy and Overwhelming Daytime Sleep Society (NODSS) of Australia offer Australia-specific information on sleep disorders including Narcolepsy, as well as Sleep Apnoea and others. They also conduct bi-monthly meetings which are held in Melbourne.

YAWNs

[HTTP://WWW.FACEBOOK.COM/GROUPS/YAWNS/](http://WWW.FACEBOOK.COM/GROUPS/YAWNS/)

This is a facebook group for Young Adults With Narcolepsy (YAWNs) where you can ask questions, get advice from others, share your own experience or simply talk about whatever you feel like with other young narcoleptic people from around the world.

Publication Details

Text for this booklet was sourced from the informative pamphlet “Narcolepsy and You,” available from the Narcolepsy Network: www.narcolepsynetwork.org/resources/educational-info

Some text has been edited to make it more appropriate for an Australian audience.

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NOTES



Awake & Aware.

FALLING ASLEEP IS THE GUIDE YOU NEED TO BECOME MORE FAMILIAR WITH THE DAY-TO-DAY ISSUES ASSOCIATED WITH NARCOLEPSY, AND HOW TO DEAL WITH THEM.

This book aims to provide information for narcolepsy patients about their condition. It gives you all the facts your doctor may have told you, along with lots more information on the effects that narcolepsy can have on your everyday life (including emotional impacts, which are often overlooked).

Reading this book, patients can learn how to best live a healthy, fulfilling life through being more aware of their condition. It can also act to refresh knowledge of some of the basics, or as a guide for the friends and family of a narcoleptic person looking to better understand and support them.