# SLEEP DISORDERS AUSTRALIA

Information about sleep disorders and where you can find help and support.



12TH EDITION

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#### DISCLAIMER

Information provided in this booklet is general in content and should not be seen as a substitute for professional medical advice. Concerns about sleep problems or other medical conditions should be discussed with your family doctor.



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## Message from the Board

Sleep Disorders Australia (SDA) is the peak patient body for sleep disorders in Australia. Sleep Disorders Australia (SDA) is a voluntary Not for Profit organisation that was established in 1994 from the amalgamation of the various State groups dealing mostly with sleep apnea. In 1985 the treatment of sleep apnea took a great leap forward with the development of CPAP for home use by Australian sleep researcher Dr Colin Sullivan. There were two sleep support groups in Australia at that time. In NSW, the Sleep Apnea Research Association (SARA) was formed with the support of the Sleep Disorders Unit of Royal Prince Alfred Hospital, and in South Australia, Apnea Incorporated was formed with the assistance of the Royal Adelaide Hospital Sleep Clinic.

SDA now provides information and offers support and assistance to people and their families who are living with a range of sleep disorders. SDA advocates for the needs of people with sleep disorders and traises awareness of sleep disorders and the significance they can have on the lives of those affected by them. We also provide support and education with regards to the prevention and treatment of sleep disorders. We work with a range of sleep health professionals, organisations, research centres and peak bodies.

It is our mission to serve the interests of all people affected by sleep disorders. To raise awareness of sleep disorders and their significance and to encourage and support the prevention and treatment of sleep disorders. To enable us to reach our goals to the best of our ability we need a broad membership base to help us better understand what those 'interests' are. Therefore, becoming a member of SDA will not only allow us to continue to do the work we do, it will give you the opportunity to have your voice heard.

SDA does not receive funding, we rely on memberships and donations to help fund the work we do. Members are important to SDA. In return for their loyalty and support, we listen to their concerns and suggestions. Please join us and help us make a difference in the lives of those affected by sleep disorders.

## Join Sleep Disorders Australia

SDA does not receive funding. We rely on membership and fundraising including donations from the community to help fund our programs. Your membership will help us continue to advocate for the needs of people with sleep disorders and to provide support and information to the community through its support services and ongoing education and awareness programs. We would very much appreicate it if you would consider joining and/or making a charitable donation to SDA.

Membership is available to all sufferers, members of their family, medical professionals, and any member of the public who has an interest in the area of sleep disorders. Join Sleep Disorders Australia and help us make a difference for all those affected by sleep disorders.

## WHAT YOUR MEMBERSHIP WILL HELP US DO:

#### Support - Advocacy - Awareness - Education

- Local get togethers where people with sleep disorders and their family and friends can meet others and get involved with local activities and events.
- Participate as consumer health advocates and patient representatives on clinical trial networks and related committees.
- Provide support and information to research centres and the Australasian Sleep Association on clinical trials and policy matters.
- We provide free information booklets and a range of individual information brochures to sleep clinics, doctors and dental surgeries, chemists and other health care professionals for patients and the public.
- Participation in awareness initiatives including World Sleep Day and various individual sleep disorder awareness events, including Sleep Apnea Awareness Day.
- We maintain a website that includes a range of factsheets and other information that you can download and share.

- Social Media channels including Facebook and Twitter.
- Facebook support group.
- Member Newsletter.
- Support by telephone, mail and e-mail.
   We give non-medical advice to people about sleep disorders, including how to get diagnosed and available treatments.
   We also answer other inquiries and send out information brochures and factsheets.
- CPAP Buddy Program A buddy program is maintained in all states to put new CPAP users in contact with more experienced users, for advice and encourgement during the difficult period of initial treatment.
- Free second hand PAP machine advertising on our website for all members. Non memberss are also welcome to advertise.

## SECOND HAND CPAP MACHINES

The SDA website carries advertisements for second hand CPAP machines for private sale. If you can't afford a new machine, you might find a solution here. Please note that all second hand CPAP machines should be serviced and calibrated to your prescription by an authorised dealer before use.

## TO JOIN SDA OR TO MAKE A DONATION

You can join SDA and donate via our website sleepoz.org.au

You can also donate via cheque. Please send your cheque to:

### Sleep Disorders Australia

PO Box 5278 Algester Qld 4115

Other payment options include:

**Direct Debit:** 

Sleep Disorders Australia BSB 062 240 Account No. 10018178

#### **PayPal**

treasurer@sleepoz.org.au

Please use your surname as the payment reference.

SDA is endorsed by the ATO as an income tax exempt charity and has endorsement as a Deductible Gift Recipient. All donations \$2 and over are tax deductible.





## Are you interested in helping others?

SDA is a not for profit organisation that is ran by volunteers. If you have time to spare, some relevant experience and would like to help make a difference in the lives of people with sleep disorders please consider volunteering with us. We need people with a range of skills that could come from experience in the sleep medicine industry, committee or not for profit management, general administration as well as graphic design and social media management. All work done for our national head office can be done remotely ie: you can do the work from home providing you have access to a reliable computer and internet access. If you are interested please contact us at admin@sleepoz.org.au

If you have any trouble logging in to our website or using our membership system please email membership@sleepoz.org.au

## Excessive Daytime Sleepiness – Finding the Cause

Excessive daytime sleepiness has a significant impact on quality of life. People with daytime sleepiness struggle with social, academic and work demands, they are at risk of motor vehicle and workplace accidents and generally have poorer health than comparable adults.

Accurate diagnosis is important, not only because of the negative impacts of sleepiness and its root causes on health and social function but because excessive sleepiness is generally remediable with appropriate treatment. The list of possible causes of excessive daytime sleepiness spans virtually every major area of medicine, neurology and psychiatry. A clear, detailed history is invaluable in negotiating these numerous diagnostic considerations.

Following is a list of known causes and routine tests to assist patients and doctors when considering the cause of excessive daytime sleepiness.

Please note: there are numerous possible causes, this is by no means a complete list. It is only intended as a guide to assist you and your doctor find the cause of your excessive daytime sleepiness.

CAUSES OF DAYTIME SLEEPINESS	
Sleep Disorders	
Behavioural sleep deprivation	The most common cause of daytime sleepiness is insufficient sleep/poor sleep hygiene.
Sleep-related breathing disorders	Sleep apnea. Residual sleepiness in treated obstructive sleep apnea.  Upper Airway Resistance Syndrome.
Other sleep disorders	Includes circadian rhythm sleep disorders (Delayed Sleep Phase Syndrome, shift work disorder), REM Sleep Behaviour Disorder and other Parasomnias, Post-traumatic hypersomnia (following head trauma or illness) Insomnia, Narcolepsy. Also sleep-related movement disorders (Periodic Limb Movement Disorder, Restless Legs Syndrome).
Psychiatric	
Mental health conditions	Mental health conditions Including Depression, Anxiety, Bipolar Disorder.
Medication effects	Includes prescription, non-prescription, and drugs of abuse. *refer to list of medications on the right.
Madical conditions	

#### Medical conditions

Including head trauma, stroke, cancer, infammatory conditions, encephalitis, neurodegenerative conditions (eg: Parkinson Disease, myotonic dystrophy etc), Chronic Fatigue Syndrome, Fibromyalgia, Hypothyroidism (Hashimotos), Ehlers-Danlos Syndrome, Arnold-Chiari Malformation, Multiple Sclerosis. Other medical conditions that are associated with sleep fragmentation can result in daytime sleepiness, including: arthritis, spondylosis, chronic pain of any nature, nocturnal angina, epilepsy, asthma, chronic obstructive pulmonary disease, alcoholism, urinary dysfunction and gastrointestinal disorders (e.g. peptic ulcer disease), gastro-oesophageal refux and irritable bowel syndrome

#### Other considerations

Hypersomnia that develops after a viral infection including mononucleosis (glandular fever/mono), or Guillain-Barre syndrome. Patients may experience fatigue and hypersomnolence and can sleep most of the 24-hour day. The outcome tends to be favourable; however, the resolution may take months or even years.

Long sleepers, also called "healthy hypersomniacs," are people who require more sleep at night than normal. They may be misdiagnosed with idiopathic hypersomnia because of extremely long sleep episodes at night. These subjects are normally alert, however, once they have obtained their required amount of sleep.

#### MEDICATION CLASSES COMMONLY ASSOCIATED WITH DAYTIME SLEEPINESS

- Alpha-adrenergic blocking agents
- Anticonvulsants (e.g., hydantoins, succinimides)
- Antidepressants (monoamine oxidase inhibitors, tricyclics, selective serotonin reuptake inhibitors)
- Antidiarrhea agents
- Antiemetics
- Antihistamines
- Antimuscarinics and antispasmodics
- · Antiparkinsonian agents
- Antipsychotics
- Antitussives
- Barbiturates
- Benzodiazepines, other aminobutyric acid affecting agents, and other anxiolytics
- Beta-adrenergic blocking agents
- Genitourinary smooth muscle relaxants
- Opiate agonists and partial opiate agonists
- Skeletal muscle relaxants

## ROUTINE TESTS TO CONSIDER FOR CAUSES OF DAYTIME SLEEPINESS

- Thyroid tests should include: TSH, Free T3 (FT3), Free T4 (FT4), Reverse T3 (rT3), and thyroid antibodies for Hashimoto's Thyroiditis
- Nutrient deficiencies including vitamin D (25-Hydroxy), B12 and serum folate, magnesium, zinc, iodine and selenium

- Iron studies: Iron, TIBC, %Sat, Ferritin
- Carnitine panel: free, total, esterified, esterified/free
- C-Reactive Protein
- Complete Blood Count
- Complete Metabolic Panel (glucose, sodium, creatinine, etc)

Cortisol (preferably 8 am spot cortisol or 24-hr urinary cortisol)



## Sleep Apnea

Sleep apnea occurs when the airway in the throat collapses during sleep reducing airflow or completely blocking the airway. This disrupts their sleep and reduces oxygen supply to vital organs. Severe sleep apnea affects about 5% of adults. Mild to moderate forms occur in 20% of adults. Fortunately, effective treatment is available and once treated the person with sleep apnea leads a normal healthy life.

The symptoms of sleep apnea. People with sleep apnea usually snore loudly and have restless sleep. Often these symptoms are not noticed by the person with sleep apnea but by their partner. The partner may also notice pauses in breathing lasting between each pause typically ends with a very deep gasping or snoring noise as the person struggles to breathe. As a result of the problems during sleep, the person with sleep apnea may be very sleepy in the day and wake in the morning feeling unrefreshed. It can affect the person's ability to concentrate and function at work. Other symptoms which can occur in untreated sleep apnea are sore throats, chronic cough, depression, apathy, irritability, reduced libido, loss of memory and concentration and increased frequency of urination at night.

Sleep apnea affects families. Snoring and apnea can be extremely irritating and disrupt the sleep of the bed partner. These problems can aggravate, or become a focus for, marital disharmony and family stress. It is made worse by the unexplained sleepiness and lack of interest in family life of the person with apnea.

Sleep apnea is associated with heart attacks and stroke. There is strong evidence that people with moderate to severe sleep apnea die prematurely. If you have sleep apnea you are more likely to have cardiovascular disease than someone without sleep apnea.

Towards the end of each apnea cycle blood pressure may rise substantially and the heart beat becomes irregular. This may lead to high blood pressure (hypertension). If you are overweight you may also be at risk of diabetes and have high cholesterol. Taken together these risk factors result in an increased chance of the person having a heart attack or a stroke.

Sleep apnea causes motor vehicle accidents. Research has shown that people with sleep apnea are at least 4 times as likely to have a motor vehicle accident. Their performance is noticeably worse as the disrupted night-time sleep leads to a reduced ability to concentrate and increased chance of falling asleep at the wheel. When sleep apnea occurs in people who have occupations involving operating machinery or transport this can be a lethal combination.

What causes sleep apnea? There are two types of apnea obstructive apnea and central apnea. Obstructive apnea is much more common and is the result of obstruction of the airway leading from the nose or mouth to the lungs. The obstruction is usually the result of a narrowed airway which becomes partly or completely blocked when the muscles around the airway relax during sleep. Central apnea is rare and results when the signals from the brain to regulate breathing are disrupted in some way.

Who gets sleep apnea? Sleep apnea can occur at any age. Childhood sleep apnea is is commonly the result of enlarged tonsils or adenoids or of some cranio-facial abnormality or severe obesity. In adulthood sleep apnea becomes more common in middle age and is more common in men than in women, although after menopause women may be at increased risk. Sleep apnea is often associated with being overweight, particularly with excess fatty tissue around

the neck. In people who are not overweight, it is likely that they have been born with a narrow airway or facial structure which leads to a narrow airway. Almost everyone who has obstructive sleep apnea snores as snoring is also the result of narrow or floppy upper airways.

How is sleep apnea diagnosed? The only way to diagnose sleep apnea is with an overnight sleep study. This can be done in the privacy of your own home. Or it can be done in a hospital while your sleep is monitored. You will need a referral from your GP or sleep physician for a sleep study.

How is sleep apnea treated? The treatment of choice for severe sleep apnea is called nasal continuous positive airway pressure or CPAP. This consists of a pump that blows air through a mask worn over the nose during sleep. The noise of the machine is generally much less obtrusive than the snoring that preceded it.

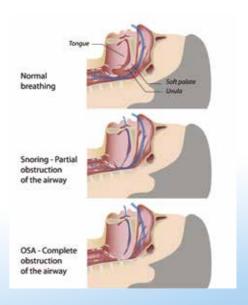
**Oral appliances** Oral appliances that fit in the mouth and hold the bottom jaw forward will reduce the severity of sleep apnea and are generally the first-line treatment option in patients with mild-moderate sleep apnea but require an experienced dentist to fit and monitor their effects. Surgical treatments are improving but it is important to find a surgeon who specializes in sleep apnea surgery. There is no effective drug for treating sleep apnea although a number have been tried. A number of other treatments have been marketed including devices to avoid sleeping on your back and nasal valves. These may help some people but it is very important that any treatment you undertake is supervised by a sleep physician and that if necessary a repeat sleep study is conducted to check the effectiveness. If your sleep apnea is not effectively treated you will remain at risk of problems related to sleepiness including workplace and motor vehicle accidents.

#### **SLEEP APNEA AND OBESITY**

In many people sleep apnea results from being overweight. If this is the case, losing weight may help or even cure the apnea but before stopping CPAP treatment you should consult your sleep physician. In any case, losing weight may be the most important thing that you can do to reduce cardiovascular disease such as high blood pressure and diabetes.

## THINGS TO AVOID IF YOU HAVE SLEEP APNEA

There are some things that make apnea worse and even if you are on CPAP treatment, should be avoided. Alcohol relaxes muscles and may worsen apnea as may sleeping tablets which depress the drive to breathe. It is advisable to try and maintain a regular sleeping pattern. Other things that disrupt sleep such as caffeine and eating late at night should also be avoided.



## **Treatments for Sleep Apnea**

## CPAP OR CONTINUOUS POSITIVE AIRWAY PRESSURE

CPAP is a very simple mechanical aid to help keep the airway open. CPAP prevents the airway closing by keeping a positive pressure inside the airway, a bit like blowing up a bicycle inner-tube that has become deflated. This pressure is created by blowing air through the nose and into the upper airways. This pressure is applied continuously throughout the night to prevent the airways closing. Hence the name: Continuous Positive Airway Pressure.

#### How is the pressure applied to the airway?

The most commonly used method for applying the pressure is by the use of a soft mask that is shaped to seal against the face or into the nose. Masks may fit over the nose only or both nose and mouth (for mouth breathers). Getting a satisfactory fit of the mask to the face is the most difficult part of CPAP treatment. Although masks have improved dramatically over the years, a number of people still have difficulty adapting to them and it is really important that you find a mask that suits you.

How long does CPAP take to work? CPAP works immediately in stopping your sleep apnea. Some people notice immediate improvement in their daytime symptoms, such as tiredness, but others find it takes some time to get used to CPAP and gain maximum benefit. If you feel that your CPAP is not working effectively you should return to your sleep specialist and get help.

**Do I need to use CPAP all night?** Yes. Unfortunately CPAP does not cure sleep apnea; it simply controls the symptoms by keeping the airway open. When you stop using CPAP your apnea will return as will your daytime symptoms. Recent studies show the more you use it the more benefit you gain. If you have a cold or flu you may be advised not to use your CPAP while nasal symptoms



are severe. As soon as you are comfortable with it you should start using it again.

What is humidification? Most CPAP machines have an optional humidifier, which warms and adds moisture to the air. This makes breathing more comfortable for many people and can help to prevent mouth leaks.

#### OTHER TREATMENT OPTIONS

While CPAP (Continuous Positive Airway Pressure) is probably the most effective for patients with severe sleep apnea, it is not well-tolerated by some people. Unfortunately, a number of people with sleep apnea do not tolerate CPAP and turn to other treatments such as surgery to the airway or an oral appliance. Oral appliances that fit in the mouth and hold the bottom jaw forward will reduce the severity of sleep apnea and are generally the first-line treatment option in patients with mild-moderate sleep apnea but require an experienced dentist to fit and monitor their effects.



#### **ORAL APPLIANCES**

Oral appliances are also called mandibular advancement splints (MAS) or mandibular advancement devices (MAD). They are worn only while sleeping. They consist of a 'mouth guard' fitted to both the top teeth and the bottom teeth. They gently hold the lower jaw forward to help open the airway by repositioning the tongue more forward. This helps to reduce the airway blockage. They fit completely within the mouth. You can speak, drink water, yawn and even kiss while wearing them. Mandibular advancement splints should be made to meticulous measurements of your mouth and jaws and this is best done by a dentist experienced in Dental Sleep Medicine.

There are a number of different styles available and a dentist experienced in the field of Dental Sleep

Medicine will advise on the most appropriate style for you. The fitting of the appliance generally requires an impression of your teeth to be taken before it is customized to your jaws and teeth. The MAS is adjusted to slowly bring the lower jaw forward and slowly reduce the sleep apnea without causing tooth and jaw discomfort. Private Health Rebates are available with Dental Extras.

#### Is it comfortable?

Yes! A properly fitted MAS should not cause discomfort to your teeth or gums or jaw. Most people find that an oral appliance is both more comfortable and more convenient than CPAP.

A number of cheaper 'boil and bite' products are available over the counter or from the internet. These cannot be recommended as they are poorly adapted to your teeth and can cause gum, tooth and jaw problems long term. They also cannot advance your jaw far enough to be effective in opening the airway. If you have tried one and it did not help your sleep, you cannot compare the outcome to that of a custom made to measure appliance made by a dentist trained in Dental Sleep Medicine.

## GOOD POINTERS TO TREATMENT SUCCESS:

- If your sleep is mild or moderate in severity.
- If your sleep is better on your side than your back.
- If you have a lower jaw that tends to recede.
- If you have a good amount of lower jaw movement.
- If you are in a healthy weight range.
- If you have central sleep apnea (more common in people with heart failure or a stroke), a MAS will almost certainly not work. Seek advice from your sleep specialist.









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## Sleep Disorders and Related Risks

## SLEEP DISORDERS AND RELATED RISKS

Sleep disorders have been implicated as risk factors in a number of other health problems. Sleep deprivation, whether due to a reduced quantity of sleep or a disturbed quality of sleep, affects a variety of essential functions and hormone balances, and contributes to an increased risk of heart disease, high blood pressure, obesity and diabetes. It affects general mental functioning, in particular, daytime alertness, mood, memory functions, and decreased learning ability. There is some recent evidence that sleep deprivation also depresses the immune system which means the body is less able to fight off viruses and infections.

## HYPERTENSION (HIGH BLOOD PRESSURE)

Hypertension is а major cause atherosclerosis (thickened artery walls) and may lead to blood clots and strokes. Hypertension can also lead to heart attacks, kidney disease, peripheral vascular disease and retinopathy. Research has shown that those who regularly get less than 5 hours of sleep per night are at a high risk. People with untreated sleep apnea are also at risk for hypertension. This may be due to the overall lack of proper sleep, or it may be as a result of the extra blood flow needed after an apnea to compensate for low oxygen levels. Research has shown that when sleep apnea patients are effectively treated, their high blood pressure goes down, not only at night, but also during the day.

#### **HEART DISEASE**

Sleep apnea starves the body's vital organs of oxygen throughout the night. This puts a strain on the heart as it tries to compensate. Researchers have found sleep apnea to be an independent risk for a variety of cardiovascular diseases, and an exacerbating

factor in nocturnal angina in patients with coronary artery disease. When breathing recommences after an apnea the heart muscles are called on for greater exertion, just at a time when their own oxygen supply has been compromised. During recent research studies, when a group of patients with heart failure were tested in a sleep study, approximately half had severe undiagnosed sleep apnea. Research is ongoing, but it seems clear that people with moderate to severe sleep apnea have an increased risk for heart attack, vascular disease and pulmonary hypertension.

#### **OBESITY**

Obesity contributes to sleep apnea, and sleep apnea contributes to obesity. In fact, most sleep disorders can contribute to obesity. Researchers have found that people who don't get enough sleep can develop increases in appetite and kilojoule intake. In a university study, they found that in the group getting less than 6 hours sleep per night, their levels of the hormone leptin fell, leading to a greater appetite. The same group also produced approximately 30% more insulin to maintain their normal blood sugar levels. Higher insulin levels are associated with higher levels of fat storage. As lack of sleep also results in tiredness and lowered activity rates, so obesity is encouraged on three fronts: higher kilojoules taken in, lower energy given out, and insulin stimulating fat storage. In the case of sleep apnea, the weight gain affects the fat in the neck, and the air passage collapses more easily, leading to a worsening of the sleep apnea, which leads to further increases in obesity, and a vicious cycle ensues.

#### DIABETES

Research has shown that short sleep duration has direct effects upon the risk of diabetes, independent of its influence upon body weight and blood pressure, and body weight and hypertension also act as partial contributors to diabetes. A study by scientists at the University of Chicago found that after restricting 11 healthy young adults to only four hours sleep for six consecutive nights, that their ability to process glucose had declined - in some cases to the level of diabetics. Other studies have shown that subjects who regularly slept 5 hours or less were twice as likely to develop diabetes over the 10 year follow-up, as those who slept 7 hours or more. Research statistics indicate that approximately 50% of men living with diabetes also have sleep apnea, and 50% of sleep apnea patients tested when attending a sleep clinic, were shown to have impaired glucose intolerance. Recent studies of young healthy males showed that sleep deprivation for only two nights increased insulin. increased ghrelin and decreased leptin, translating into decreased glucose tolerance and an increased appetite for carbohydraterich foods. One research article concluded that "If short sleep duration increases insulin resistance and decreases glucose tolerance. then interventions that increase the amount and improve the quality of sleep could serve as treatments and primary preventative measures for diabetes".

#### **BRAIN FUNCTIONING**

Studies have shown that normal humans require between 7 and 9 hours of sleep per night. There has been a lot of research looking at the effects of sleep deprivation on various brain functions. People asked to perform tasks after spending a night without sleep, had impaired abilities comparable to people under the influence of alcohol. A lack of sleep most notably impacts on attention and working memory, which can have disastrous consequences in road accidents, operating machinery, forgetting about fire hazards, etc. People who are sleep deprived

have impaired learning abilities, slower reaction times and poorer judgment. Severe sleep deprivation can lead to low mood, psychosis and hallucinations.

#### **SEXUAL FUNCTION**

Sleep apnea has been shown to be associated with impaired sexual function for both men and women. Excessive tiredness can contribute to a low libido, as can a reduction. in hormone levels such as testosterone. which can occur as a result of sleep apnea. Many factors can contribute to declining erectile function, one of which is untreated sleep apnea. This can be due to blood vessel walls not expanding as well as they should to allow for increased blood flow, or a decline in testosterone, or impaired night time erections due to broken sleep associated with sleep apnea. Treatment of sleep apnea has been shown to improve erectile function in about half of men who have both sleep apnea and erectile dysfunction

People suffering from disorders with related risks should discuss with their doctors whether their sleep problems may be contributing to their other disorders. Treating your sleep problem may help to improve other conditions.

SDA has a variety of
Fact Sheets available that
you can download from the
SDA website at
www.sleepoz.org.au

### Insomnia

**Insomnia** is a common and distressing difficulty in falling asleep, going back to sleep, or waking too early.

Causes of Insomnia. There are many different causes of insomnia. Some medical conditions may cause insomnia, particularly pain, chronic respiratory problems, or other sleep disorders. Some medications such as blood pressure tablets or asthma medication. as well as substances like caffeine (coffee). nicotine (smoking) and alcohol, may trigger insomnia or make it worse. Psychiatric conditions such as depression and anxiety are common in insomnia and may cause insomnia. Other precipitating factors for insomnia include illness, loss, death of a family member/friend, financial stresses, and work and relationship issues. Even when these triggers are no longer present or reduced at least to some extent, the insomnia can continue. Insomnia can be a vicious cycle, in that the more you worry about not sleeping, the harder it is to get to sleep.

Insomnia Treatments. Just as there are many causes for insomnia, there are many treatments. In most people, the insomnia will get better by itself. If insomnia persists, the best treatment is Cognitive Behaviour Therapy (CBT) provided either individually or in a group by a psychologist or even-on line through specific programs. A psychologist can help you to re-schedule your sleep and wake times, improve your sleep habits, improve stress management, and control unwanted thoughts and worries about your sleep. Information and education about sleep habits and expectations form part of most CBT programs.

The main goal of any treatment for insomnia is to break the vicious cycle that keeps the insomnia going. Attention to simple things such as getting up at the same time, going to bed only when sleepy and comfortable, reducing caffeine and alcohol, getting enough exercise, minimizing light exposure and having some fun can help you to sleep. Ask your GP for a referral to a psychologist. A certain number of sessions with a sleep psychologist are subsidised by Medicare.

Cognitive Behavioural Therapy (CBT) Treatment is about making both behavioural (doing) and cognitive (thinking) changes to your life and sleep. They are not easy but they work! TRY:

- Reducing the time you spend in bed.
   Many people compensate for poor sleep
   by spending more time in bed, to give
   themselves more time to fall asleep or
   go back to sleep. Unfortunately, this
   behaviour leads to even worse sleep.
   Choose and keep the same getting up time
   no matter what your sleep has been like
   the night before this will help to re set
   your brain clock on a daily basis.
- Getting up and going to another room if you are unable to go to sleep or go back to sleep within around 15 minutes. Read or listen to music in dim light. When you are feeling less tense and more comfortable go back to bed and see if you can "let go" and let sleep happen. You MAY need to do this a number of times a night and for a number of nights to get your sleep back into a better pattern. Then let bed be a place where you go to when you are feeling comfortable and sleepy not a place where you are trying hard to go to sleep or are awake tossing and turning and worrying.
- If there is an underlying medical condition that is contributing to the insomnia get help from your GP to address it so that you can work on the behavioural and/ or psychological cause/s. You may need a referral to a sleep psychologist to help

you do this. Psychological assistance with stress management, relaxation and controlling thoughts are key factors in "retraining in sleep" as can attention simple environmental factors (comfortable mattress, being too hot, too cold, wearing earplugs because of noise). Information and education about sleep and expectations about sleep will help you to understand what you can do yourself to improve your sleep. Collectively these factors outlined help in promoting healthy sleep. Recent research has shown that these treatments together increase deep sleep more than sleeping tablets alone.

Sleeping Medication. Sleeping tablets may be prescribed for short-term insomnia but may lose their effect after a few weeks. Stopping sleeping medication may result in a few nights of much worse sleep which is called rebound insomnia. It is therefore better to gradually reduce sleeping tablet use rather than stop abruptly. Make sure the risks and benefits of sleeping medications are fully discussed wth your doctor.

Starting Treatment. See your family doctor first to discuss your sleeping difficulties.

Your doctor can then undertake a proper assessment, initiate treatment or refer you to a sleep disorders clinics, sleep specialist or to a sleep psychologist.



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## **Narcolepsy**

Narcolepsy is an uncommon but very debilitating neurological sleep disorder.

#### **SYMPTOMS**

Narcolepsy is characterised by a combination of symptoms. Sufferers differ in the combination and severity of these symptoms, but they are generally:

- Drowsiness during the day this is often described as tiredness, lack of energy, exhaustion, or a combination of these feelings either continuously or at various times throughout the day. Sometimes sleepiness occurs so suddenly and with such overwhelming power that it is referred to as a "sleep attack". These "sleep attacks" may be as short as one minute or as long as an hour. The sufferer usually wakes up feeling refreshed and may then be alert for another hour or more. However, drowsiness may continue throughout the day.
- Cataplexy sudden loss of muscle function.
   In severe instances the cataplexy may result in a collapse, although the person remains conscious throughout the episode.
   In less severe forms it may show as just a weakness in the knees, jaw or facial muscle droop or possibly an inability to speak clearly. It may last from a few seconds to a few minutes and is usually triggered by a sudden emotional reaction such as laughter, anger or fear.
- Sleep Paralysis can happen when waking up or when falling asleep. Although the person is not fully awake they are aware of the paralysis and are unable to move any part of the body except perhaps the eyes. It may last from a few seconds to a few minutes. This can be extremely frightening but it is not dangerous. Sleep paralysis is not restricted to people with narcolepsy about 15% of the population may also experience it.

- Hallucinations some people with narcolepsy have dream-like hallucinations just as they are falling asleep or waking up. (Hallucinations when falling asleep are known as hypnagogic; when waking up, hypnopompic). These hallucinations can be quite vivid and may be frightening, such as a sense of a threatening stranger or dangerous animal in the room.
- Disturbed night-time sleep and vivid dreams – sleep is often disrupted by periods of wakefulness and vivid dreams which can worsen daytime sleepiness.

#### WHAT CAUSES NARCOLEPSY?

Scientists believe that Type 1 Narcolepsy (Narcolepsy with cataplexy) is caused by a lack of the chemical known as hypocretin (also referred to as orexin) in the brain. Hypocretin is an important chemical for regulating wakefulness and rapid eye movement (REM) sleep. Type 2 Narcolepsy (without cataplexy) includes some of the same symptoms as Type 1 Narcolepsy, however, its cause is unknown.

#### **HOW IS NARCOLEPSY DIAGNOSED?**

To be sure of the diagnosis doctors need to check that there isn't another condition that is causing the symptoms. This involves medical tests and a comprehensive medical history. A full sleep study that includes a polysomnogram (PSG) and a multiple sleep latency test (MSLT) is also done. The PSG is a nighttime test and a MSLT is the daytime component. The results of the sleep study combined with the medical tests and comprehensive medical history help doctors determine whether a patient has narcolepsy.

#### **HOW IS NARCOLEPSY TREATED?**

There is no cure for narcolepsy, however some of the symptoms can be managed with medicines and lifestyle changes. It may take some time to find the best treatment as not all medicines and lifestyle changes are appropriate for everyone.

## Idiopathic Hypersomnia

Idiopathic Hypersomnia (IH), sometimes referred to as Idiopathic Hypersomnolence, neurological sleep/wake disorder characterised by excessive sleep and daytime sleepiness. It is a debilitating condition often profoundly affecting work, education and relationships.

Most people can feel tired, fatigued and at times, excessively sleepy, particularly when they do not get enough sleep. However what sets people with IH apart, is that they experience extreme sleepiness despite getting adequate, or typically more than adequate, hours of sleep. Their sleep may be deep and uninterrupted, but it is not refreshing. Despite extraordinary amounts of good quality sleep people with IH are in an almost constant state of sleepiness.

#### **SYMPTOMS**

The main symptom of IH is excessive deep sleep. Despite adequate and often extraordinary amounts of good quality sleep (eg: 11 hours or more per night) people with IH still feel excessively sleepy during the day. Other symptoms typically include:

- Chronic excessive daytime sleepiness often resulting in long daytime naps.
- Long and unrefreshing naps. Naps are usually more than one hour long and are typically not refreshing.
- Extreme and prolonged difficulty awakening from sleep, confusion, disorientation, irritability and poor coordination, with an uncontrollable desire to go back to sleep. It can also be accompanied by automatic behaviour (performing tasks without consciously knowing it and not remembering you have done them eg: turning off alarm clocks or answering your phone). This is clinically known as "sleep drunkenness".
- Cognitive dysfunction (commonly referred to as 'brain fog'): problems with memory,

automatic behaviour, concentration and attention.

Unlike in other sleep disorders, the sleep in patients with Idiopathic Hypersomnia is normal; there are no disturbances that can account for these symptoms.

#### **DIAGNOSIS**

Diagnosing IH can be difficult as excessive daytime sleepiness can be caused by various disorders and/or conditions as well as numerous medications. A physical examination, medical tests and a comprehensive medical history are necessary to rule out all other possible causes. including insufficient sleep. Sleep studies involving a Polysomnography (PSG) followed immediately by a Multiple Sleep Latency Test (MSLT) are also carried out to exclude other sleep disorders such as sleep apnea. The sleep patterns during a sleep study in patients with Idiopathic Hypersomnia are normal.

#### TREATMENT AND MANAGEMENT

There are no medications specifically for Idiopathic Hypersomnia. Medications used to treat Narcolepsy, including stimulants and wake-promoting medications, are prescribed to counter the daytime sleepiness, however there are no medications currently available that assist with cognitive dysfunction or extreme difficulty waking up and sleep drunkenness. Stimulant and wake-promoting medications can be helpful to relieve sleepiness for some patients, however they are rarely effective long term. Some people with IH find a combination of medication and lifestyle changes are helpful in managing their symptoms. Lifestyles changes can be difficult to initiate (and maintain) for people with chronic illness and may need the assistance of a specialist therapist.

More information can be found at www.hypersomnolenceaustralia.org.au

## Circadian Rhythm Disorders

Circadian Rhythm Sleep Disorders are a group of sleep disorders that affect the timing of sleep, characterised by an inability to sleep and/or wake at normal or appropriate times due to the dictates of the individual's biological or circadian clock.

People with circadian rhythm sleep disorders are therefore unable to sleep and wake at the times required for normal work, school, and social needs, which can severely impact their quality of life.

#### CIRCADIAN RHYTHM SLEEP DISORDERS INCLUDE:

## Advanced Sleep-Wake Phase Syndrome - ASPS

Advanced sleep-wake phase syndrome involves a shift in the circadian rhythm that leads to a strong, sometimes irresistible need to fall asleep in the early evening, generally between 6 p.m. and 9 p.m., and wake up very early in the morning, generally between 2 a.m. and 5 a.m.

#### Delayed Sleep Phase Syndrome - DSPS:

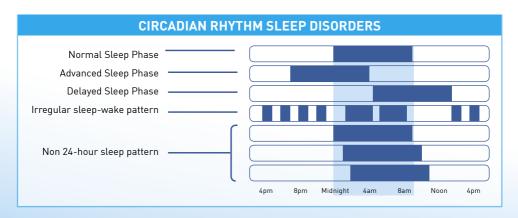
Delayed Sleep Phase Syndrome involves a shift in the circadian rhythm that is opposite to ASPS. People with DSPS are unable to fall asleep until very late at night and not wake up until much later in the day.

#### Irregular sleep-wake rhythm

Irregular sleep-wake rhythm is a rare form of circadian rhythm sleep disorder. It is characterised by numerous naps throughout a 24-hour period, no one main sleep episode that occurs at any time of day and irregularity from day to day. During the day, it may seem like they are sleepy because they nap so much. During the night, it may seem like they have insomnia because they are awake for long periods of time during the night. The total time asleep per 24 hours is normal for the person's age.

#### Non-24-hour Sleep-Wake Disorder

The sleep time of people who have Non-24-Hour Sleep-Wake Disorder shifts a little later every day. Sleep time and wake up time continue to move later and later every day. Every day, morning light and other behaviors reset the sleep-wake clock to a 24 hour schedule. Without light or if there is a fault with this clock resetting, people's sleep time will drift later and later. This is why many people who have Non-24-Hour Sleep-Wake Disorder are blind.



## **PLMD**

Periodic Limb Movement Disorder (PLMD) is characterised by repetitive limb movements that only happen when you are asleep and occur repeatedly every 10 to 60 seconds. These movements usually involve the legs: however, the arms may also be involved in severe cases. They occur in periods lasting anywhere from a few minutes to several hours

The PLMD patient is often identified by the bed-partner's complaints of being kicked. Abnormal limb movements result in daytime tiredness by causing periods of wakefulness during the night (called arousals) and disrupting the brain's sleep-patterns. The abnormal movements also prevent the brain from transitioning into stages of deep sleep, causing the sufferer to wake feeling tired and unrefreshed. PLMD is also often disruptive for the sufferer's bed partner.

PI MD occurs commonly with more advancing age. It affects 25% of people aged 50-60 and up to 44% of people 65 and older. PLMD can occur in conjunction with other sleep-disorders, such as narcolepsy, obstructive sleep apnea, or REM-behaviour disorders. As many as 80% of people with RLS also have PLMD and as they may have trouble both falling asleep and staying asleep, they usually suffer from fatigue or sleepiness during the day.

Cause of PLMD The exact cause of PLMD is still unknown. Scientists believe that the underlying mechanisms probably involve abnormal nerve transmission in parts of the nervous system that influence sensation, although studies have not revealed any consistent abnormalities.

How is PLMD treated? If PLMD is causing disrupted sleep and daytime symptoms, it may be necessary to treat the disorder. The same drugs that are used to treat RLS

may be used eg: dopaminergic medications, calcium channel blockers (Pregabalin and Gabapentin), opioids (such as codeine) and benzodiazepines (eq. Clonazepam. diazepam). These medications treat the symptoms of PLMD, and not the underlying cause. Consequently, they must be taken every evening before bed, otherwise the symptoms will return. Controlling caffeine intake, alcohol, and smoking may also help.



### SLEEP DISORDERS **AUSTRALIA**

SDA is run by volunteers as a non-profit charity. We are the only national body in Australia that represents ALL sleep disorders and the people that are affected by them.

SDA needs members to enable us to continue to offer advice and support and to raise awareness of the affect sleep disorders have on people's lives.

Help us to be more effective by becoming a member. The larger our membership base, the louder our voice.

Please help us to make a difference. You can join SDA and donate via our website sleepoz.org.au. (or for more details turn to page 5 of this booklet)

### Restless Legs Syndrome

RLS. also called Willis-Ekbom Disease. is a neurological movement disorder characterised by uncomfortable sensations in the legs or sometimes the arms, that results in the compelling urge to move the affected limbs. It occurs in both genders, however if is more common in women. Symptoms can begin at any age, but are more common and more severe in older people. As many as 7-10% of the population are affected, with varying degrees of intensity. Up to 40% of women will experience RSL symptoms during pregnancy. There is no test for RLS, and there is usually nothing abnormal for a doctor to detect on examination

#### **Symptoms**

People with RLS describe an irresistible urge to move the legs when the sensations occur. Usually, moving the legs, walking, rubbing or massaging the legs, or doing knee bends can bring relief, at least briefly. If the legs are not moved, they can twitch/jerk involuntarily. Symptoms are usually worse in the evening and may make falling asleep very difficult, a condition called Sleep Onset Insomnia. If sufferers do manage to fall asleep, leg movements may lead to frequent awakenings, a sense of insomnia and as a result they have unrefreshing sleep. It is easy to see why RLS sufferers complain of irritability, anxiety, and depression.

#### How do I know if I have RLS?

- You have a strong urge to move your legs when sensations of crawling or tingling occur.
- Your symptoms occur when you are at rest, such as sitting or lying down.
- Your symptoms decrease when you move or massage the affected limbs.
- Symptoms are worse in the evening or when trying to sleep.
- Symptoms are not attributed to another

medical condition like, nocturnal leg cramps, arthritis, peripheral neuropathy.

## The cause is generally unknown, however, certain factors may be associated:-

- RLS may be hereditary. There is 30-50% greater chance that you will develop RLS if your ancestors had it.
- RLS may occur during pregnancy, especially during the final trimester. The symptoms usually disappear after delivery.
- Low iron levels or anaemia may worsen symptoms. Low iron in the brain has been linked to RLS.
- Chronic diseases may lead to RLS, particularly kidney failure. Other diseases such as diabetes, rheumatoid arthritis, Parkinson's disease or damage to the nerves of the arms, hands, legs, or feet (i.e. peripheral neuropathy) may also be associated with RLS.
- High caffeine (coffee), sugar, alcohol intake and smoking may make RLS worse.
- Attention deficit hyperactivity disorder (ADHD) is common in children and adults with RLS.

Treatments If a cause such as anaemia can be identified, treating this may resolve the RLS. Otherwise, in mild cases, some people find that activities such as taking a hot bath, massaging the legs, using heat pads or ice packs, exercising, and eliminating caffeine help to alleviate symptoms. In more severe cases, medications are prescribed. Unfortunately, no one drug is effective for everyone with RLS, and a medication that is initially effective may lose its effectiveness with prolonged use. Symptoms tend to get worse over time, and it may be necessary to change medications to keep symptoms under control.

If you have concerns about RLS, you should discuss them with your family doctor.

## Sleepy Drivers Die

Insufficient sleep has significant consequences on health and well-being including serious injury and even death. A study by Deloitte Access Economics estimates more than one Australian will die every day, or 394 a year, from falling asleep at the wheel of a vehicle, or from industrial accidents, due to lack of sleep.

Many Australians don't realise that driving when sleep-deprived can be just dangerous as driving while intoxicated by alcohol or drugs. Extreme tiredness brought about by not enough sleep puts drivers at a much higher risk of nodding off, however driver fatigue can also impair reaction time and decision making, which further increases the risk of being involved in an accident.

Australian research shows drivers who have had 17 hours of sleep deprivation face the same risk of a crash as a person who has a blood alcohol concentration of 0.05 g/100ml. To put that into an everyday scenario, if you woke up at 6am to go to work, then went out for dinner and were driving home at 11pm, that's 17 hours. You would therefore be twice as likely to have an accident as a person with a zero blood alcohol content who is not fatigued. When you consider that one in every five car accidents is related to fatigue. it amounts to a lot of harm caused by people not getting enough sleep.

#### Signs of Drowsiness:

- Heavy eyelids, eyes closing, frequent blinking, or trouble focusing
- Trouble keeping your head up
- Drifting between lanes, hitting a shoulder
- Constant yawning, rubbing your eyes
- · Daydreaming/wandering thoughts
- Difficulty concentrating on driving, missing exits or traffic signs



#### Tips for Staying Safe on the Road:

- Make sure you have had plenty of sleep before you leave
- Be aware of the effects of medications you are taking (some may increase drowsiness)
- If you have to drive a long distance, share the driving with someone else
- Don't rush. It's better to arrive at your destination safe than on time
- Do not drink alcohol. Even very small amounts of alcohol will enhance drowsiness
- Avoid driving between 1am and 6am, this is a time when sleepiness is most intense
- Do not rely on short-term remedies to offset the feelings of fatigue e.g., turning up music, drinking coffee/energy drinks etc. If you feel tired or notice signs of drowsiness pull over and take a short power nap

If you are feeling sleepy, stop driving immediately. The only cure for sleepiness is sleep.



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