

Sleep

A Mind Guide to Parkinson's Disease



About this book

GLOSSARY

Definitions for all words underlined in blue can be found in the glossary starting on page 32. A comprehensive Parkinson's disease glossary can be found at [Parkinson.org/glossary](https://www.parkinson.org/glossary).

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An index of key words and topics can be found on page 36.

PARKINSON'S FOUNDATION RESOURCES

Certain pages include tip sheets with practical pointers. You can find more helpful tips for managing Parkinson's in the books, fact sheets, videos and newsletters in our PD library at [Parkinson.org/library](https://www.parkinson.org/library). In particular, watch "Sleep and Parkinson's" from our Expert Briefings webinar series.



Sleep is essential for overall health and wellbeing. Unfortunately, problems with sleep and alertness are common in Parkinson's disease (PD). It is likely that you will experience poor sleep and/or impaired daytime alertness at some point in the course of your disease – maybe you already have. These problems can have a big impact on your quality of life, as well as significant safety implications: for example, if you get sleepy while driving. There are many causes of sleep problems in PD, but they are often under-reported by people with Parkinson's and caregivers and under-recognized by healthcare professionals.

Consider this your practical guide for achieving good sleep health. This book addresses healthy sleep, sleep changes due to aging and sleep problems due to Parkinson's, as well as diagnosis, treatment and coping strategies. The information, tips and stories included here will provide answers, help you organize thoughts and questions for your medical team and remind you that you are not alone on this Parkinson's journey.

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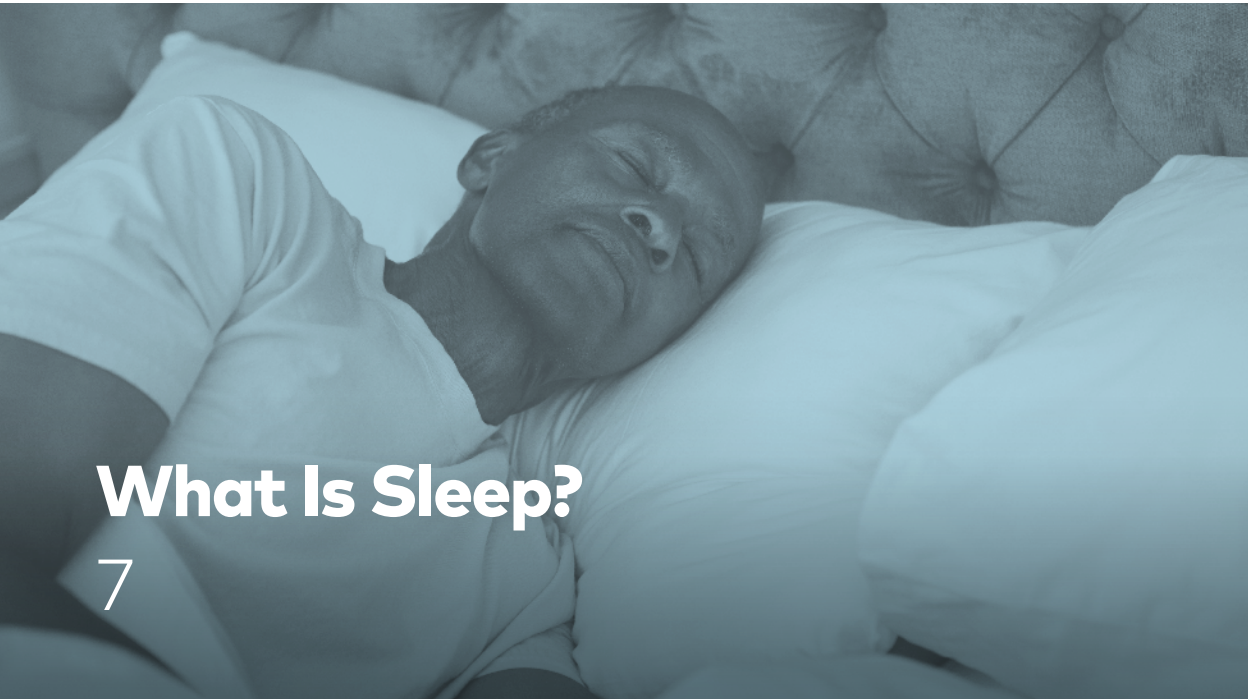
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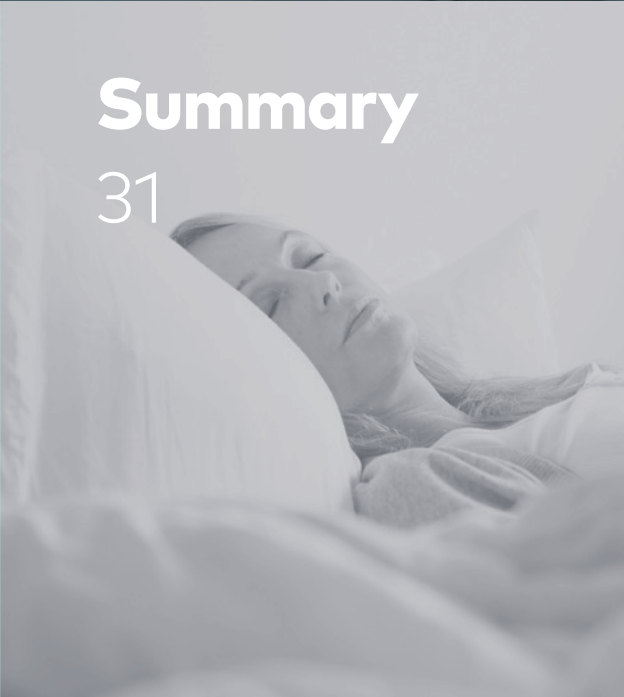
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Acknowledgements

This book was written and reviewed by:

Aleksandar Videnovic, MD

This book has been made possible through the generous donations of thousands of individuals affected by Parkinson's.

CHAPTER ONE

About Parkinson's Disease

If you're reading this book, you are probably already familiar with Parkinson's disease, but here are some basics: Parkinson's is a progressive neurodegenerative disorder that affects about one million people in the United States and 10 million people worldwide. It is called a movement disorder because of the tremors, slow movements, stiffness and muscle cramping it can cause. But its symptoms are diverse and usually develop slowly over time.

Parkinson's disease is not diagnosed with a test or a scan; instead it is diagnosed by a neurologist, who asks you questions about your health and medical history and observes your movement. Your doctor may want you to have some tests or imaging; some, like an MRI, can help rule out other conditions, while others, like DaTScan, may help confirm a Parkinson's diagnosis if there is uncertainty. The goal of treatment is to help you manage your symptoms. Good symptom management can help you to stay healthy, exercise, and keep yourself in the best possible shape. Although at this time there is no way to correct the brain changes that cause Parkinson's, we know that exercise can help you maintain your

ability to fight the disease and that staying healthy can reduce setbacks that make PD progress faster. Great care is an important part of living your best life with Parkinson's.

Lack of [dopamine](#) in people with Parkinson's was first described in the 1960s. Dopamine is a type of [neurotransmitter](#), or chemical messenger, one of several chemicals your brain cells use to send signals to one another. Soon after, dopamine-replacement therapy using [levodopa](#) became – and remains – the gold standard treatment. However, we know that the dopamine system is not the only one affected by Parkinson's. The disease process also disrupts other brain networks, including those linked to mood, behavior and thinking (cognition). You might also hear that Parkinson's is linked to a protein in the human brain called [alpha-synuclein](#). Researchers continue to study how cells and brain networks are affected in Parkinson's to improve our understanding of the disease and potential for treatments.

You and your family may have questions or fears about Parkinson's and genetics. While there are several genetic mutations that can increase your risk, for the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible factors involved in – not necessarily causes of – disease development.

Sleep and Parkinson's

James Parkinson, an English surgeon, provided the initial description of the disease, later to be named after him, in 1816. In his famous monograph "Essay on the Shaking Palsy," Parkinson described six of his patients, including comments about their sleep habits. He wrote:

"In this stage, the sleep becomes much disturbed. The tremulous motion of the limbs occur during sleep, and augment until they awaken the patients, and frequently with much agitation and alarm."

These two-hundred-year-old writings are the first description of sleep dysfunction among people with Parkinson's. Today, it is well recognized that sleep problems are a significant non-motor feature of the disease.

CHAPTER TWO

What Is Sleep?

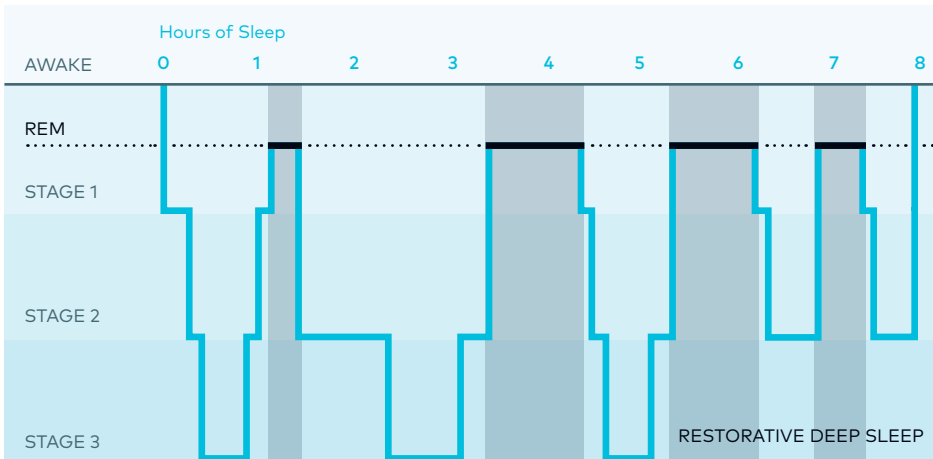
We spend approximately one-third of our lives sleeping, so it is important that we pay attention to the amount and quality of sleep we get.

What Is the Purpose of Sleep?

While there is still debate about the exact function of sleep, we know that it is essential for energy restoration, immunity, learning, growth and development. Recent studies point to the critical role of sleep in clearing waste products from the brain. This has significant implications for neurodegenerative disorders, including Parkinson's and Alzheimer's diseases, where abnormal proteins build up in brain cells.

We also know what happens when you do not get enough sleep. Lack of sleep leads to poor physical and cognitive performance.

Sleep Stages



When you sleep, your brain does not! You continuously cycle between rapid eye movement (REM) sleep and non-rapid eye movement (non-REM, or NREM) sleep. NREM sleep is further divided into three stages:

Stage 1 (N1) is the transition stage between wakefulness and sleep. You might still be aware of sounds and activities around you, and it's easy to be woken up from this stage.

Stage 2 (N2) is when your heart rate slows and your body temperature drops. Muscle activity decreases as your body gets ready for deep sleep.

Stage 3 (N3) is the deep sleep stage, when the beneficial functions of sleep occur: the body repairs and regrows tissues, builds bone and muscle and strengthens the immune system. Breathing and heart rate, body temperature and blood pressure are all at their lowest points during this stage.

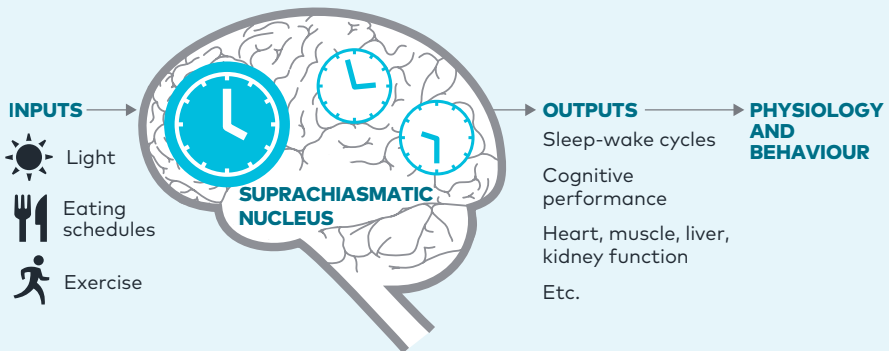
In **REM sleep**, as its name suggests, your eyes move rapidly. Your heart rate and breathing quicken because your brain is more active. This stage is associated with dreaming, and the length of REM sleep periods increases as the night goes on. Most people do not move while they dream, even if they are moving a lot within their dream. The brain does not send signals to the muscles during REM sleep. This is called sleep atonia. In Parkinson's, however, many people experience REM sleep behavior disorder (RBD). People with RBD act out their dreams. (See page 18 for more information.)

The Body Clock

Circadian rhythms (from the Latin "circa," meaning "around," and "diem," meaning "day") are physical, mental and behavioral changes that follow a roughly 24-hour cycle. These rhythms respond primarily to light and darkness in our environment. This is why we tend to get tired as it gets darker – and get tired earlier in the winter when it gets dark earlier – and wake up with the sun. In addition to regulating the sleep-wake cycle, circadian rhythms affect almost all other processes in our body: temperature, blood pressure, heart rate, hormone secretion and more.

In turn, a group of nerve cells called the suprachiasmatic nucleus (SCN) controls the circadian system. The SCN is the body's master biological clock. It aligns our body cycles with the rotation of Earth and keeps time for the rhythmic changes in bodily functions during a 24-hour day. Signals from the SCN travel to the pineal gland, which secretes the hormone melatonin. Melatonin levels rise toward the end of the day, signaling nighttime and preparing us for sleep. Levels remain high throughout the night, then drop in the early morning as the sun rises, causing you to wake up.

Parkinson's Disease Disrupts the Circadian System



How Much Sleep Do I Need?

There are individual differences in how much sleep we need. Our sleep needs change with age and the presence of health issues. But in general, large, population-based studies suggest an average of seven to eight hours of sleep per night is the optimal amount for adults. Getting too little sleep results in "sleep debt." If we do not repay this debt, we face the consequences of sleep deprivation: daytime sleepiness, poor judgment and impaired reaction time, among others. These effects negatively impact quality of life and have safety implications for you and those around you.

However, in Parkinson's it may be more important to focus on sleep quality rather than number of hours slept. If the quality of your sleep is good and you wake up feeling rested and energized, you may not need eight hours of sleep a night.

Sleep, Lifestyle, and Environment

We live in a society that is constantly on the move. While this can make us feel productive and efficient in our daily lives, many of our behaviors can interfere with the sleep-wake cycle. For example, many people rely on caffeine, from coffee to energy drinks, to get them through the day. Similarly, excessive and untimely exposure to noise and artificial light from our many screens – television, computer, smartphone – can cause problems with the timing, continuity and duration of our sleep.

Do Parkinson's Medications Affect Sleep?

Some PD meds, like MAO-B inhibitors (selegiline, rasagiline, safinamide) and amantadine (a medication used to treat dyskinesia), have alerting properties and may make insomnia worse. These medications are usually taken earlier in the day, so they do not impact sleep. Sinemet does not usually have a big impact on sleep compared to dopamine agonists. However, nighttime hallucinations can emerge with increased intake of dopaminergic drugs, especially in people with more advanced Parkinson's. There are other possible causes of hallucinations, so if you begin to experience this, talk to your doctor right away. For more information on hallucinations, read or download our book *Psychosis: A Mind Guide to Parkinson's Disease* online or request a print copy at [Parkinson.org/books](https://www.parkinson.org/books).

Tips For A Good Night's Sleep – Sleep Hygiene

Sleep hygiene is the habits that promote better quality sleep. Just as you brush your teeth and floss to maintain good dental hygiene, there are things you can do to improve nighttime sleep and daytime alertness.

Set a schedule: Going to bed and getting up at the same time helps set good sleep-wake rhythms.

Limit naps: Daytime naps may make it hard to fall asleep and stay asleep at night. But not all naps are bad: studies have shown that short naps (lasting 15–20 minutes) may improve mood, alertness and performance on activities of daily living and other tasks.

Spend time in natural light: Light helps set our internal clock. Studies have linked daytime exposure to natural light with sounder sleep.

Exercise: Regular physical exercise promotes good sleep. However, give yourself a few hours between your workout time and bedtime to allow your body temperature, heart rate and adrenaline levels to lower.

Avoid caffeine, nicotine, and alcohol: Caffeine and nicotine are stimulants and may cause insomnia. Alcohol may help you fall asleep, but as it is metabolized, "[rebound insomnia](#)" can appear, interrupting sleep.

Relax: Establish a relaxing routine before bedtime. Anxiety is one of the main culprits of insomnia, and relaxation rituals – like listening to music or taking a warm bath – can help you settle down.

Regulate bedroom temperature: Cooler is better for sleep. A lower core body temperature signals sleep. But try to avoid temperature extremes in your sleeping environment. Environments that are too cold or too warm are not conducive to good sleep.

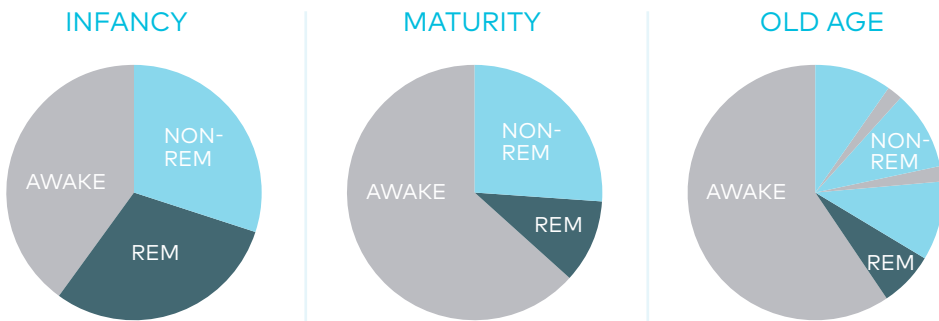
Get into bed only when you are sleepy, and don't lie in bed awake: If you can't sleep, get out of bed and do an activity until you feel tired. Read a book, do a puzzle, play solitaire – avoid artificial light from screens like a TV, smartphone or computer.

Seek help as needed: Timely and accurate diagnosis of a sleep disorder is important not only for good sleep but for your overall health. Talk to your healthcare provider if you do not have restful sleep.

It can also be helpful to keep a sleep journal, so you can recognize patterns and share it with your doctor if needed. Together you can identify things that aid sleep and habits that can be improved for better sleep.

Sleep In Healthy Aging

Both our sleep patterns and our sleep structure change as we age. Older people tend to become sleepy earlier in the evening, prompting them to fall asleep and wake up earlier than when they were younger. Furthermore, “deep sleep” (stage 3 NREM sleep) diminishes, and “light sleep” (N1 and N2) dominates throughout the night. Changes to our internal clock, the suprachiasmatic nucleus, likely underlie this phenomenon.



Despite these changes to sleep patterns and structure, sleep needs remain relatively unchanged as we age. Older individuals need between seven and nine hours of sleep, just like younger adults.

The main sleep complaints reported by older people are difficulties falling asleep and staying asleep. These troubles can negatively impact daytime alertness and overall energy level. There are several possible reasons for these sleep changes:

- The aging process
- Emerging sleep disorder unrelated to Parkinson's
- Physical or psychiatric disorder unrelated to Parkinson's
- Parkinson's disease

CHAPTER THREE

Sleep Disorders

It is estimated that more than 50 million Americans suffer from a sleep disorder. The healthcare burden of these disorders is close to \$20 billion annually, and the indirect costs – due to the impact on workforce and productivity – are much larger.

Parkinson's is associated with unique problems with sleep and alertness. Up to 80% of PD patients report poor sleep.

Insomnia

Insomnia is the inability to sleep. It includes difficulty falling asleep and staying asleep, as well as waking up too early in the morning. About one third of the adult population has some symptoms of insomnia, and it is even more common in people with PD. Insomnia can be brief and acute (episodic) or it can be chronic. Chronic insomnia is diagnosed if symptoms persist at least three nights per week for at least three months.

People with Parkinson's usually fall asleep without much trouble but wake up frequently throughout the night and report difficulties falling back to sleep. These problems with sleep maintenance are the most common type of insomnia in PD.

The most common results of insomnia are sleep that does not refresh you, fatigue or low energy, and mood disturbances. People affected by insomnia have decreased performance at work because they are too tired or have trouble concentrating. Insomnia can also negatively affect personal relationships.

There are many causes of insomnia in general, and in people with Parkinson's in particular:

- Women and elderly people are more likely to experience insomnia.
- People with more advanced PD have more prominent insomnia compared to those with milder disease.
- Other medical and psychiatric conditions contribute to insomnia in people with PD. For example, mood disorders such as anxiety and depression can lead to difficulties falling asleep.
- Undiagnosed primary sleep disorders such as obstructive sleep apnea (see page 22) or restless legs syndrome (see page 26) may cause insomnia.
- Sleep continuity in people with PD can be affected by rigidity, tremor that returns when you wake up during the night, pain and nocturia (excessive urination during the night), among other symptoms. When sleep continuity is interrupted, it is called sleep fragmentation.
- Certain dopaminergic therapies can also negatively influence sleep quality. For example, MAO-B inhibitors and amantadine (a medication used to treat dyskinesia) have alerting properties and may make insomnia worse.

Diagnosis

Like for Parkinson's disease itself, there is no definitive diagnostic test for insomnia. The most important step in establishing an accurate diagnosis is a clinical interview with your healthcare provider, who will ask questions to get a detailed medical and sleep history. Make sure to share your sleep schedule (both weekdays and weekends), your sleep environment (including the presence of pets), how often you have problems sleeping and what you do when you are unable to fall asleep. Your doctor may ask you to fill out a sleep diary or refer you to a sleep laboratory for an overnight sleep study (see page 20 for more information).

Treatment

There can be many insomnia triggers, so treatment depends largely on what is causing it. The treatment approach should be tailored for each person. Acute or situational insomnia may not require treatment. For example, insomnia due to jetlag will resolve on its own. Treatment of chronic insomnia, on the other hand, requires a more active approach.

Cognitive behavioral therapy (CBT) is a technique that helps people change patterns of negative thinking and behavior. It is commonly used to treat mood disorders such as depression and anxiety, but it can also target thoughts and actions that are disruptive to sleep. In fact, the issues are related, as relieving anxiety can improve sleep. CBT has been studied in people with PD and found to be effective in treating insomnia. Over the course of several months, a cognitive behavioral therapist can help you replace anxiety related to poor sleep with positive thoughts that associate being in bed with being asleep. This will likely include many strategies, such as stimulus control, relaxation, sleep hygiene and sleep restriction. You will share your thoughts about sleep and work with the therapist to set a sleep schedule that will ultimately – hopefully – lead to a good night's sleep.

Another technique that has been studied in people with Parkinson's is light therapy. In this treatment, you are exposed to light that is brighter than indoor light but not as bright as direct sunlight. In these studies, light boxes were used once or twice per day in 30- to 60-minute blocks, resulting in improved sleep quality, sleep continuity and daytime alertness. Because of its effectiveness, low cost and excellent safety profile, light therapy is a promising treatment not only for impaired sleep and alertness but also for other aspects of PD, such as depression. Like any treatment, do not

start light therapy without consulting your healthcare provider. If not done properly – for example, if you have light exposure too late at night – it can be harmful and disrupt your sleep-wake cycle even more. There are also some special considerations. For example, light therapy may cause mania, hyperactivity and agitation in people with bipolar disorder.

Other than CBT and light therapy, there have not been a lot of clinical studies focused on the treatment of insomnia associated with Parkinson's. Many of the behavioral techniques that have been used to treat insomnia in the general population are used in CBT, so they can be beneficial for people with PD. Talk to your healthcare provider – and ideally a sleep physician – about incorporating these strategies into your routine:

- Relaxation therapy includes various techniques to reduce anxiety and body tension. This might include deep breathing, meditation, [guided imagery](#), [biofeedback](#), [progressive muscle relaxation](#) and more.
- Sleep restriction may be considered if you spend too much time in bed unsuccessfully trying to fall asleep. This intervention initially limits the number of hours you sleep, then gradually increases sleep time until a normal night's sleep is achieved.
- Reconditioning encourages use of your bed for the sole purposes of sleep and sex. Only get in bed when sleepy or for intimate purposes. If you cannot fall asleep, leave the bedroom and return when you are sleepy again.

If these non-pharmacological therapies fail to improve your sleep, several medications may be considered. Any medication adjustments should be made with the guidance of your healthcare provider.

- Sometimes underdosing or wearing-off of levodopa at night can lead to poorly controlled symptoms. Taking a nighttime dose of controlled- or extended-release carbidopa-levodopa (Sinemet CR or Rytary, respectively) may improve sleep.
- Several studies of dopamine agonists reported improvements in sleep quality. However, dopamine agonists have been associated with nightmares and vivid dreams, as well as daytime sleepiness and sleep attacks. Discuss these issues with your doctor if you are considering a dopamine agonist primarily to treat insomnia or poor sleep.
- Clinical studies have shown that treating depression in Parkinson's improves symptoms of insomnia. Therefore, a well-selected antidepressant may be a good treatment choice.
- Prescription sleep medication eszopiclone (brand name Lunesta) may also be considered.
- The over-the-counter supplement melatonin is another option, though it should still be taken with the guidance of your doctor.

Only as a last resort should sedatives such as zolpidem (common brand: Ambien) be used. These drugs can be addictive, so that you are not able to fall asleep without them. They can also contribute to grogginess during daytime and lead to troubling behaviors, such as nighttime eating disorders.

NOTE

For more information on sleep and Parkinson's disease, tune into Episode 46 of our podcast *Substantial Matters: Addressing Sleep Discomfort with Parkinson's* at [Parkinson.org/Blog](https://www.parkinson.org/blog).

REM Sleep Behavior Disorder

REM sleep behavior disorder (RBD) belongs to a group of sleep disorders called "parasomnias." These are conditions that involve abnormal or unusual movements, behaviors, emotions, perceptions, and dreams that happen when you are falling asleep, during sleep, or as you are waking up. As its name suggests, RBD occurs during REM sleep cycles, the period of sleep when you dream. There are two main hallmarks of this disorder:

1. Loss of muscle paralysis (atonia) during REM sleep.
2. Vivid and usually unpleasant dreams that people frequently refer to as nightmares.

Normally when you sleep, your brain prevents thoughts about moving from turning into signals to make your muscles move. If you have RBD, the system that prevents those signals from going to your muscles stops working automatically. This means that your dreams about moving result in your brain telling your muscles to move. Since your muscles are free from the normal paralysis of REM sleep, you can speak, move and "act out" your dreams, which may be vivid or intense. For example, the dreams might involve being chased, battling with fire or arguing with someone. This can result in screaming, yelling, kicking, punching or diving out of bed, placing you and your bed partner at risk for injuries.

About 50–60% of people with Parkinson's have RBD. In fact, in many people it is one of the early signs of PD. Healthy individuals diagnosed with RBD are at significantly increased risk for developing Parkinson's down the road. This process may be long, even several decades, but RBD is now considered one of the first potential markers of the ongoing neurodegenerative processes that underlie PD.

Diagnosis

Diagnosis of RBD starts with a detailed sleep interview. Since you may not remember your dreams or be aware of your overnight vocalizations and movements, an interview with a bed partner, if you have one, is also helpful.

There are several conditions that can mimic RBD, so it is important for your healthcare provider to rule out other options. Sleep interruptions during REM sleep from sleep apnea (see page 22) may be wrongly interpreted as RBD. Other parasomnias, such as sleepwalking, sleep talking and night terrors, can mimic RBD and are commonly confused for it. And rare forms of seizures and epilepsy may result in behaviors that resemble RBD. Because of this, you should rely on your doctor to help you diagnose RBD.

The frequency and intensity of RBD symptoms change over time. Some people experience RBD long before their Parkinson's diagnosis, while others develop RBD years later. Not all RBD is violent. You might have several episodes of vivid dreams and "acting out" during one night followed by a quiet period of several days, or the events may be more evenly spread throughout the week. It is not uncommon to hear reports that someone used to have RBD symptoms but does not anymore.

Ultimately, if your doctor strongly suspects RBD, you will be referred to a sleep lab for an overnight sleep study. If the study shows loss of muscle paralysis during REM sleep – through recordings of muscle activity via electrodes placed on different parts of your body (see below) – a diagnosis of RBD is confirmed.

Almost 10 years ago, Elena noticed that her husband, Paulo, started moving a lot while he slept. One night he punched her in the arm and left her with a bruise. It didn't happen every night, but a couple times a week he would thrash and scream. It woke her up and made her nervous. She felt lucky he didn't punch her in the face! They made an appointment with Paulo's primary care doctor, who referred him for a sleep study after hearing about his nighttime behavior. A sleep specialist diagnosed him with RBD and recommended some precautions: remove sharp objects from around the bed, and sleep in separate beds or even separate rooms if the outbursts continued. Just last year, Paulo received another diagnosis: Parkinson's disease. His neurologist told him that it is common for people with RBD to develop Parkinson's later on.

What Is a Sleep Study?

When it comes to diagnosing sleep disorders, often more information is needed than can be gathered in an office visit. In this case, a sleep study might be recommended. Just as your doctor evaluates your motor symptoms by observing you doing various tasks (e.g., tapping your forefinger and thumb together as fast as you can), during a sleep study your sleep is recorded and monitored.

Most sleep studies are done in a sleep laboratory that is set up for overnight stays and is made comfortable and dark for overnight sleeping. This is usually at a hospital or sleep center, which can be found in most communities. You may bring personal items related to sleep and wear your own pajamas. Some sleep tests can be done at home, but these can only test for breathing disorders such as sleep apnea (see page 22).

A sleep technologist will put sensors on your head and body, but these should not interfere with your comfort or movement. An electroencephalogram (EEG) will monitor your sleep stages and cycles of REM and NREM sleep, while other sensors measure your eye movements, heart rate, breathing, blood oxygen levels, snoring, and limb movements. Your doctor will use this data to figure out if you have a sleep disorder, and if so, which one.

Treatment

Timely and accurate diagnosis of any health condition is important. For RBD, it can help prevent significant injuries, as well as sleep fragmentation. Treatment starts with education for you and your bed partner. Safety comes first: sharp objects should be removed from the sleeping environment, and furniture may need to be padded at corners. If you have severe symptoms, it can help to put soft objects, such as cushions or pillows, on the floor in case you fall out of bed while acting out.

The main medications used to treat RBD are melatonin and clonazepam, though exactly how they work to treat RBD is not known. Melatonin is a hormone that is naturally produced by the pineal gland in the brain. However, melatonin levels slowly drop with age, and some older people might not produce any at all. Taken as a supplement in low doses (3–12mg), it is generally well-tolerated by people with PD. Caution is advised with doses higher than 9mg, as the medication may cause confusion and hallucinations in the elderly. Take your melatonin dose an hour to an hour and a half before bedtime. It is safe to take nightly as continuous therapy.

Clonazepam (brand names Klonopin, Rivotril and others) belongs to the class of medication called [benzodiazepines](#). These drugs have sedating and muscle relaxing properties and can be used to treat anxiety. In very small doses (starting at 0.25mg up to 1–2mg) clonazepam can treat RBD. Benzodiazepines are fast-acting but habit forming, so melatonin should be tried first. In particularly stubborn cases, a combination therapy of clonazepam and melatonin may be needed.

Both clonazepam and melatonin can cause morning drowsiness, which can contribute to falls. Pay attention to how you feel in the morning, especially when you first start treatment, and report any issues to your healthcare team.

Several other medications have been used for RBD, but there is no strong evidence of their efficacy.

Disordered Breathing: Sleep Apnea

Sleep-disordered breathing is the general term for breathing problems that happen during sleep. These problems range from simple snoring to sleep apnea.

Sleep apnea occurs when your breathing is repeatedly interrupted during sleep. This is caused by the partial or complete collapse of the airway. When your airway collapses during sleep, the oxygen level in your blood drops, your blood pressure rises and your heart rate slows. You end up waking up frequently, sometimes gasping for air, because the brain is not getting enough oxygen. These symptoms may repeat hundreds of times a night. However, you may not even know that you are waking up so many times, as the breathing pauses may be very brief, so-called microarousals. Frequently it is your bed partner who brings it to your attention.

There are two forms of sleep apnea:

1. In **obstructive sleep apnea**, the more common form, the main culprit is the collapse of the soft tissue in the back of the throat. This can happen because of loss of muscle tone due to aging or because of fat build-up.
2. **Central sleep apnea** occurs because of problems with the neurons that control breathing during sleep. They fail to signal the muscles to breathe. This form of sleep apnea is seen in several neurological disorders, including Parkinson's.

People with **complex, or mixed, sleep apnea** experience both obstructive and central apneas.

NOTE

The term hypopnea refers to abnormally slow or shallow breathing. This happens when the airway is partially blocked. Breathing flow is reduced but does not stop, as happens with a complete collapse of the airway.

The most common symptoms of sleep apnea are:

- Loud, chronic snoring
- Gasping and choking after a pause in the snoring
- Sleep fragmentation
- Morning headaches
- Dry mouth upon awakening
- Daytime sleepiness
- Difficulties with concentration and overall mental functioning

In addition to these immediate consequences of sleep apnea, there are several long-term negative effects on overall health. People with untreated sleep apnea are at increased risk of high blood pressure, heart arrhythmias, heart attacks, strokes and type 2 diabetes. They are also at increased risk for automobile accidents compared with the general population.

TIPS FOR BED PARTNERS

Sleeping in the same bed with someone who has apnea can disrupt your sleep, too. If you notice that your bed partner is snoring loudly or pausing their breathing during sleep, encourage him or her to talk to a healthcare provider. Treatment is important for your partner's health and your own! You will both sleep better if your partner seeks treatment for apnea, and this can have a positive effect on your relationship.

Diagnosis

About 20 million Americans have sleep apnea, though it is likely underdiagnosed. Older adults are significantly more likely to have sleep apnea, and it is more common in men than women. Research suggests that sleep apnea occurs at about the same rate in the Parkinson's population as in the general population, but the primary symptoms tend to be different. For example, in general, individuals who are overweight and report snoring and excessive daytime sleepiness should ask their healthcare provider about the possibility of a consultation with a sleep specialist. However, people with PD and co-existent sleep apnea tend not to have higher than normal body mass. Like with Parkinson's, not all symptoms are present in everyone with sleep apnea. Another example is post-menopausal woman, in whom fatigue is commonly the only symptom of sleep apnea.

Sleep apnea is diagnosed by doing an overnight sleep study. This can be done in a sleep lab or at home. If you do a home sleep test, you will be given the following sensors (and instructions on how to use them):

- A thin tube to measure airflow through your nose and mouth
- An elastic band placed across the chest and abdomen to measure respiratory effort
- A finger probe to measure blood oxygen levels

A sleep physician will interpret the results and may recommend treatment based on the findings.

TIP

If you believe you have sleep apnea, discuss it with your primary care provider, who can refer you for an evaluation with a sleep specialist.

Treatment

Treatment options for sleep apnea depend on its severity. Mild apnea may improve with weight loss and by avoiding sleep on your back. Anti-parkinsonian medications may help by decreasing the rigidity of the chest wall, allowing more normal movement with breath. Special dental devices can also be helpful for some people. These are similar to a sports mouth guard or orthodontic retainer. They hold the jaw in a position that allows the upper airway to remain open.

The gold standard in the treatment of obstructive sleep apnea is nasal positive airway pressure (PAP). With this approach, you wear a mask connected to a machine – a continuous positive airway pressure (CPAP) machine – that blows air at a pressure that is sufficient to keep the airway open during sleep. If you have a hard time adjusting to the machine, you can try PAP desensitization: using the machine during the daytime, usually during sessions with a sleep technologist.

Roger was diagnosed with Parkinson's about three years ago. While he had always snored throughout their marriage, Roger's wife complained that his snoring had worsened, and she finally gave up and moved into the guest bedroom. At his next neurologist appointment, Roger's wife brought up his snoring after reading about sleep apnea in one of their Parkinson's reference books. Roger's neurologist suggested a sleep study, and he was diagnosed with obstructive sleep apnea. Roger didn't think he could adjust to sleeping with a CPAP machine, but found it was much easier than he thought. He no longer struggled to stay awake while driving to work (a problem he had blamed on his Parkinson's medications), he had more energy throughout the day and his morning sore throats were gone.

Restless Legs Syndrome

Restless legs syndrome (RLS), also called Willis-Ekbom disease, causes unpleasant sensations in the legs, resulting in the urge to move them. Moving around relieves the symptoms, but only temporarily; the uncomfortable sensations return soon after you stop moving. People use different terms to describe the sensations: creepy-crawly, throbbing, pulling, water running down legs and achy, to name a few. Symptoms frequently make it hard to fall asleep, and they often come back if and when you wake up during the night. This can lead to insomnia and excessive daytime sleepiness.

There are several possible causes of RLS:

- It often runs in families.
- It can be secondary to iron and vitamin deficiencies, kidney failure, diabetes and peripheral neuropathy (weakness, numbness and pain in the limbs from nerve damage).
- Medications – including drugs used to treat nausea, psychosis, depression, colds and allergies – can cause RLS symptoms.
- Pregnancy, especially in the third trimester, is associated with RLS that goes away after the baby is born.

If there is no known direct cause, RLS is called primary or idiopathic. (Similarly, most Parkinson's disease is idiopathic.) If RLS is related to another disorder, it is called secondary.

As its name suggests, RLS symptoms classically affect legs, but other body parts may experience symptoms, as well. Many people with RLS have periodic limb movements of sleep (PLMS). These are involuntary, twitching movements during sleep that occur every 15–40 seconds and last for part of the night or even the entire night. However, PLMS is not always associated with repeated awakenings that disrupt sleep. While about 80% of people with RLS also have PLMS, most people with PLMS do not have RLS.

RLS affects 2–3% of the adult population, but the rate is twice as high in women. Reports vary widely on how common RLS is in people with PD. This wide range is the result of different methodologies and definitions of RLS used in studies that examined how common is RLS in Parkinson's.

Diagnosis

Like for Parkinson's (and insomnia), there is no single test that can diagnose RLS. Diagnosis of RLS is based on the clinical interview. Neurological examination, blood tests and review of medications can help identify secondary causes and rule out RLS mimics. This is especially important in people with Parkinson's, where PD symptoms may confound RLS diagnosis. These symptoms include akathisia (restlessness), frequently seen in PD, and achy feelings that are due to PD-related stiffness.

Treatment

For secondary RLS, it is important to first try to address the underlying condition (e.g., iron deficiency, diabetes, etc.).

Several medications have been proven effective for RLS. Some of these medications – mainly dopamine agonists (ropinirole, pramipexole, rotigotine) – are also used to treat PD, although in much higher daily doses. Levodopa is also effective in alleviating RLS symptoms, but it is associated with a phenomenon known as [augmentation](#). Over time, people with RLS have a tendency to become tolerant to the medication. Continued treatment with drugs that have lost benefit can worsen symptoms. With augmentation, symptoms may start earlier in the day, be more severe, and move to other parts of your body. These effects are drug-induced and are greater than the natural progression of the condition.

Nerve pain medications, such as gabapentin and pregabalin, may be effective for RLS, and they are less associated with development of augmentation compared to dopamine agonists and levodopa. Opioids are also effective in the treatment of RLS, but should be the last resort for treatment given their addictive properties and other potential side effects.

Restless legs syndrome runs in Pam's family. Her mom and aunt have it, too. Pam's mom mentioned a home remedy that worked for her. She put a bar of soap in her bed between the mattress and the bottom sheet. It took about two weeks to feel the effect, but after that she didn't feel the creepy-crawly or throbbing sensations anymore. She continued to change her sheets on a regular basis and replaced the bar of soap about every three months. Pam thanked her mom for the tip and did her own research. She couldn't find any information on why it would work, so she brought it up with her doctor. The doctor said that while there's no scientific evidence for it, it can't hurt to try.

Daytime Sleepiness

Daytime sleepiness is characterized by persistent, extreme sleepiness during the day. Up to 50% of people with Parkinson's experience excessive daytime sleepiness (EDS) at some point during the course of their disease.

The impact of excessive daytime sleepiness was largely brought to the attention of the Parkinson's community in the late 1990s, when a doctor published cases of his patients treated with dopamine agonists who were falling asleep at the wheel. The report coined the term "sleep attack": when without warning you get so overwhelmingly sleepy that you cannot take appropriate protective measures.

Several things can lead to excessive daytime sleepiness:

POOR SLEEP WITH CO-EXISTING SLEEP DISORDERS

All of the sleep disorders described above can contribute to daytime sleepiness.

MEDICATION

Dopaminergic medications, including levodopa and dopamine agonists, have been linked with excessive sleepiness and sleep attacks. In fact, about 30% of people with PD developed sleepiness in clinical studies that examined effectiveness of these medications. They have the most significant negative effects on alertness when used in combination. Antipsychotics and antidepressants can also contribute to sleepiness.

MEDICAL AND/OR MENTAL HEALTH DISORDERS

Mental health disorders, especially depression, have been associated with sleep maintenance insomnia and early morning awakenings that may ultimately result in poor alertness during the day.

CHANGES IN THE BRAIN

The same changes that lead to Parkinson's motor symptoms can affect mood, thinking, and other aspects of your health, including the sleep-wake cycle. Key brain areas for EDS are the brainstem and hypothalamus.

Diagnosis

Diagnosis of excessive sleepiness starts with a conversation with your healthcare provider. People with daytime sleepiness report drowsiness and mental foggy that may lead to problems at work and with relationships. Several conditions, such as fatigue and depression, can mimic excessive sleepiness, but there are differences. For example, when you're sleepy, you want to fall asleep and can do so easily. On the other

hand, people with fatigue report a lack of energy but may not be able to easily fall asleep during the day. For an accurate diagnosis, it is important to be open with your provider about what you are experiencing.

There are several questionnaires that may be used to diagnosis excessive sleepiness and can help measure sleepiness over time. Most common are the Epworth Sleepiness Scale (ESS), which is useful for all adults, and two PD-specific scales, the Parkinson's Disease Sleep Scale and SCOPA-SLEEP. In addition to the questionnaires, there are tests that can be done in a sleep laboratory to objectively assess how sleepy you are:

- The **multiple sleep latency test** measures how quickly you fall asleep in a quiet environment during the day.
- The **maintenance of wakefulness test** measures your ability to stay awake and alert during the day.

At his regular Parkinson's check-up, Mario told his neurologist that he has been feeling pretty sleepy during the day, but he's been coping by drinking lots of coffee, blasting music in the car with the windows down, and other little tricks. His doctor warned him that the transition to sleep can happen within a minute, without warning, so driving is not safe. This was tough news for Mario to hear, especially since he is single and does not have good public transportation where he lives. The neurologist adjusted Mario's dopaminergic medication and advised him to talk to friends and neighbors for transportation help until they figure out a treatment regimen to address the sleepiness.

Treatment

The treatment of EDS in PD has not been well studied. If a primary sleep disorder is suspected because of nocturnal activity or snoring, referral to a sleep laboratory for monitoring is a good idea.

Your doctor may adjust, reduce, or replace your dopaminergic medications, particularly dopamine agonists. If daytime sleepiness does not respond to these measures, the use of "wake-promoting" medications can be considered. These include bupropion (common brand: Wellbutrin), methylphenidate (common brands: Concerta, Ritalin), modafinil (common brand: Provigil), and, as a last resort, amphetamines. Amphetamines are rarely used for sleepiness in PD because they have addictive properties, can disrupt nighttime sleep, and can impact your heart.

Studies suggest that light therapy (see page 15) may reduce excessive sleepiness in PD.

The Epworth Sleepiness Scale

The Epworth Sleepiness Scale is used to determine the level of daytime sleepiness. Use the following scale to choose the most appropriate number for each situation:

- 0 = would never doze or sleep.
- 1 = slight chance of dozing or sleeping
- 2 = moderate chance of dozing or sleeping
- 3 = high chance of dozing or sleeping

Fill in your answers below.

| SITUATION | CHANCE OF DOZING OR SLEEPING | |
|--|------------------------------|--|
| Sitting and reading | | |
| Watching TV | | |
| Sitting inactive in a public place | | |
| Being a passenger in a motor vehicle for an hour or more | | |
| Lying down in the afternoon | | |
| Sitting and talking to someone | | |
| Sitting quietly after lunch (no alcohol) | | |
| Stopped for a few minutes in traffic while driving | | |
| Total score Add the scores; this is your Epworth score: | | |

A score of 10 or more is considered sleepy.

A score of 18 or more is very sleepy.

If you score 10 or more on this test, you should consider whether you are getting enough sleep, need to improve your sleep hygiene and/or need to see a sleep specialist. These issues should be discussed with your healthcare provider.



Summary

Good sleep is important for everyone, but especially for people with Parkinson's. There is a phenomenon known as "sleep benefit" in PD. People have reported that after a good night's sleep, they wake up feeling as if they are in the "on" state for some time, even before their next dose of medication begins working. Unfortunately, Parkinson's is commonly associated with sleep disruption and excessive daytime sleepiness. Sleep problems are under-reported by people with PD and under-diagnosed by health professionals. It is therefore important for you to think about your sleep, talk about it with your care partner(s) and family and discuss any problems with your healthcare team. Proper treatment of sleep dysfunction will likely have big benefits for your daily quality of life and overall health.

Glossary

Glossary terms are identified with a blue underline the first time they appear in this book.

- A Alpha-synuclein** A protein in the human brain that is associated with the development of Parkinson's; it is the main component of Lewy bodies
- Augmentation** A worsening of restless legs syndrome (RLS) symptoms (earlier onset of symptoms during the day, faster onset of symptoms at rest, spreading of symptoms to upper limbs and trunk) after treatment with dopaminergic medication
- B Benzodiazepine** A class of medication that leads to sedation and muscle relaxation; used to treat anxiety and in small doses sometimes used to treat REM sleep behavior disorder (RBD)
- Biofeedback** The use of electronic devices to help learn to consciously control some of your bodily functions, such as breathing and heart rate
- C Circadian rhythm** Physical, mental and behavioral changes that follow a roughly 24-hour cycle and respond to environmental cues like lightness and darkness as well as temperature
- Continuous positive airway pressure (CPAP) machine** A machine that blows air into your airway (through a mask) at a pressure that is sufficient to keep the airway open during sleep; used to treat sleep apnea
- D Desensitization** Decreasing response after repeated exposure; in the context of sleep, refers to using a CPAP machine during the daytime, usually during sessions with a sleep technologist, to get used to it if you have a hard time adjusting to the machine at night

Dopamine A chemical messenger (see [neurotransmitter](#)) that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain; in people with Parkinson's, the cells that make dopamine are impaired or die

E Electroencephalogram (EEG) A test that detects electrical activity in your brain using small sensors attached to the outside of your head

G Guided imagery A technique in which you are taught to visualize detailed images under the guidance of a therapist; may be used to help focus on calming images, for the purpose of relaxation

H Hypopnea Abnormally shallow breathing

I Idiopathic Refers to a condition for which the cause is unknown

L Levodopa The medication most commonly given to control the motor symptoms of Parkinson's; it is converted in the brain into [dopamine](#)

M Melatonin A hormone made in the pineal gland that is tied to the sleep-wake cycle; levels rise toward the end of the day, signaling nighttime, and drop in the early morning, causing you to wake up

Microarousals Repeated, brief awakenings during sleep; a common occurrence in people with [sleep apnea](#)

N Neurodegenerative disorder A disease characterized by the loss of cells of the brain or spinal cord, which over time leads to dysfunction and disability; Parkinson's disease, Alzheimer's disease and Lou Gehrig's disease are all examples

Neuron Brain cell

Neurotransmitter A chemical messenger, such as [dopamine](#), that transmits nerve impulses from one nerve cell to another, allowing them to communicate with each other

Nocturia Having to wake up frequently during the night to urinate

Non-rapid eye movement (NREM) sleep Dreamless sleep; divided into stages of increasing depth, including “deep sleep” when the body repairs and regrows tissues, builds bone and muscle and strengthens the immune system; breathing and heart rate, body temperature and blood pressure all reach their lowest points

P Parasomnias A group of conditions that involve abnormal or unusual movements, behaviors, emotions, perceptions and dreams that happen when you are falling asleep, during sleep or as you are waking up

Periodic limb movements of sleep (PLMS) A parasomnia that involves involuntary, twitching movements during sleep that occur every 15–40 seconds and last for part of the night or even the entire night

Progressive muscle relaxation A relaxation technique that involves focusing on tightening and relaxing different muscle groups

R Rapid eye movement (REM) sleep A phase of sleep characterized by rapid eye movements, faster pulse and breathing and dreaming; thought to be involved in the process of storing memories and learning

Rapid eye movement (REM) sleep behavior disorder (RBD)

A parasomnia in which you physically act out dreams

Rebound insomnia The return of insomnia after you stop use of a controlled substance, like alcohol or a medication

Restless legs syndrome (RLS) A sleep disorder that causes unpleasant sensations in the legs, resulting in the urge to move them

S Sleep apnea The main form of sleep-disordered breathing; occurs when your breathing is repeatedly interrupted during sleep, caused by the partial or complete collapse of the airway

Sleep atonia Temporary muscle paralysis that occurs during sleep to keep the body from physically acting out dreams; not present in people with REM sleep behavior disorder (RBD)

Sleep continuity The amount and distribution of being awake and being asleep in a given sleep period; includes both sleep initiation (falling asleep) and sleep maintenance

Sleep-disordered breathing A general term for breathing problems that happen during sleep, from snoring to sleep apnea

Sleep fragmentation When your sleep continuity is interrupted

Sleep maintenance Staying asleep after falling asleep; people with sleep maintenance insomnia fall asleep easily but cannot stay asleep

Sleep restriction A sleep intervention that limits the number of hours you sleep, then gradually increases sleep time until a normal night's sleep is achieved

Suprachiasmatic nucleus (SCN) A group of nerves that controls the circadian system; the body's master biological clock

V Vivid dream A dream that is very realistic or feels as though you are immersed in the dream environment

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