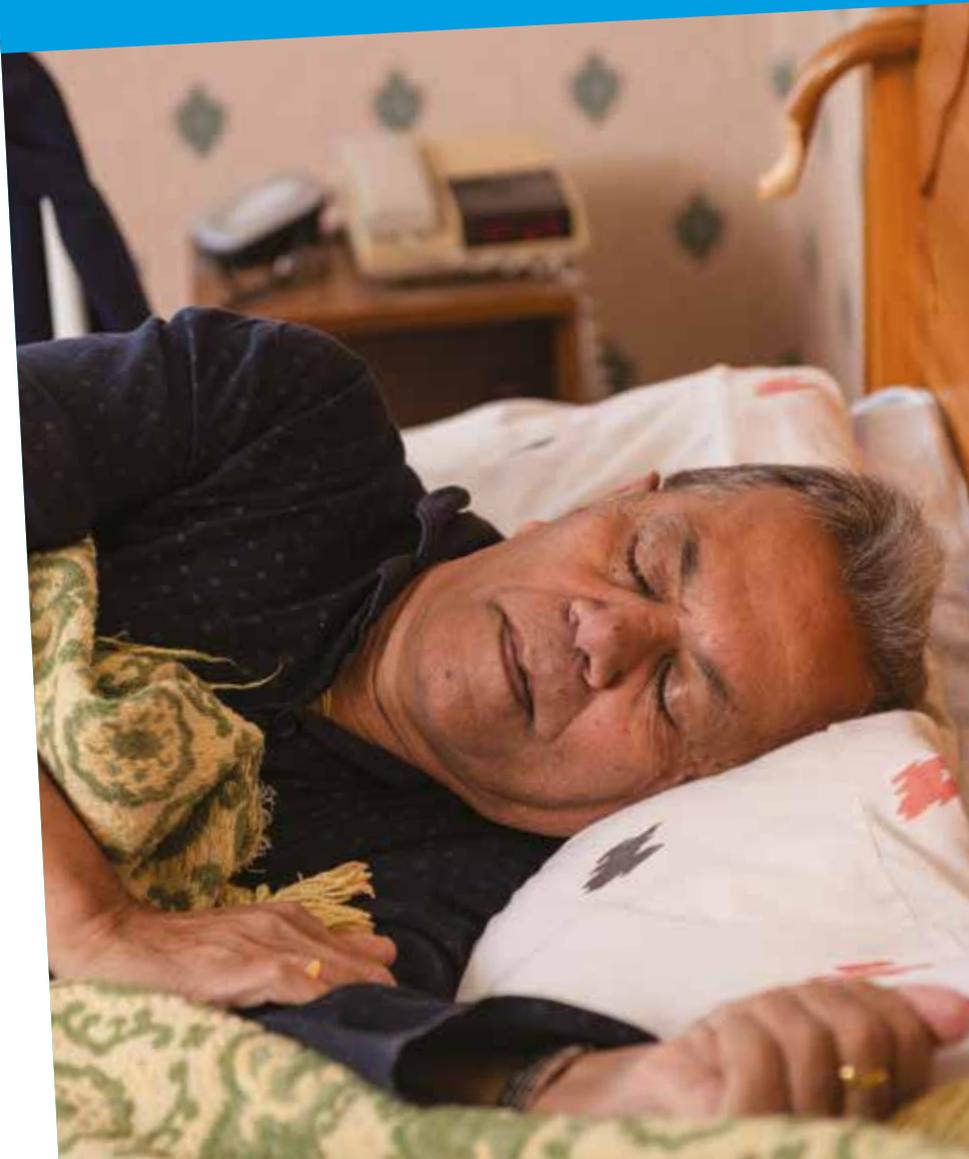


SLEEP AND NIGHT-TIME PROBLEMS IN PARKINSON'S

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



Sleep and night-time problems are common in Parkinson's. They can affect you at any stage of the condition and may leave you feeling tired and drowsy during the day.

This booklet looks at the difficulties you may experience with sleep, why this happens and what can be done to help.

A note for carers

Sleep and night-time problems are almost twice as common among carers of people with Parkinson's than in the general population.

If you are caring for someone with Parkinson's, these sleep disturbances may lead to an increased risk of depression and stress.

It may be difficult sometimes, but if you're a carer it's important to have good sleeping habits. This will help improve your health, wellbeing and general quality of life. Much of the information in this booklet applies to you as a carer as well as the person you care for.

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SLEEP PATTERNS

Most people have a 'normal' sleep pattern. This means they have a regular time when they are tired and need roughly the same amount of sleep each night.

Sleep patterns are set by your body clock, which follows the 24-hour day. Moods and feelings also affect your sleep pattern. This is why, even if it's your usual bedtime, you can stay alert and awake for longer if you're enjoying the company of friends or family, or busy with an activity that interests you. It also explains why it can be hard to fall asleep at your usual time if there's something on your mind or you're in an unfamiliar place.

In everyday life, habits and routines support normal sleep patterns. Keeping regular hours and getting up at the same time every day helps to set your body clock, making you feel tired at roughly the same time each night. Bedtime routines help you get ready to fall asleep and a familiar bed and bedroom add a sense of

calm and security. We call this good 'sleep hygiene'.

How sleep can be affected

When routines and habits are disturbed, sleep is too. This often happens (at least for a night or two) when you go away on holiday, or when you're ill. Usually these episodes don't last long, and routines and sleep patterns soon return to normal.

If there are other things affecting your sleep, your habits and routines may also be disturbed. If this happens, you may stop feeling tired at bedtime and your bedroom may not feel like a place of calm and security. It then becomes difficult to get into the right frame of mind for sleep.

This means that sometimes, even if the original cause of your sleep problem is sorted out or reduced, you can still have difficulties.

Insomnia

Insomnia is a sleep disorder that causes problems getting to sleep or staying asleep at night, so you are likely to feel tired during the day.

If you're having trouble sleeping, a cycle can develop. If you can't get to sleep, then you can become irritated, fed up, or even anxious about how you will cope the next day. These feelings tend to make you more alert, which keeps you awake, and so on. For many people, this is the start of insomnia.

Insomnia symptoms

Symptoms of insomnia are common in most long-term conditions.

People with Parkinson's can be more prone to insomnia because of Parkinson's symptoms, such as tremor, stiffness, pain and restless legs syndrome (see page 16), that can all disturb sleep.

Side effects of medication

Some medications can act as stimulants and keep you awake. Speak to your GP, specialist or Parkinson's nurse (if you have one) for advice about Parkinson's symptoms or medication if you think these are stopping you from sleeping.



IMPROVING SLEEP HYGIENE

If you are having trouble sleeping, there are simple things you can do that may help. One of the first things you can do is to improve your 'sleep hygiene'.

This means dealing with the simple things that help or hinder you sleeping. Here are 10 sleep hygiene 'rules', recommended by psychologists, and details about why each is important.

1 Don't have caffeine before you go to bed.

This includes tea, coffee, chocolate and cocoa. Many soft drinks also contain caffeine, so check the labels. Caffeine is a stimulant, which means it can make you feel more awake. Its effects can last for three to four hours. If caffeine is affecting your body at bedtime, it can increase the time it takes you to get to sleep and make sleep lighter and more restless. It is also important to limit the total amount of caffeine you drink during the day too.

2 Avoid drinking alcoholic drinks four to six hours before bedtime.

Alcohol can make you feel sleepy. But as its effects wear off we get what's called 'withdrawal' and that has the opposite effect. Although alcohol can help you get to sleep, the withdrawal effect can lead to restlessness and waking up during the night.

Another effect of drinking alcohol at night is nocturia – the need to get up and go to the toilet, which will also disturb your sleep.

3 Try not to smoke around bedtime or when awake during the night.

Like caffeine, nicotine is a stimulant and the effects are similar, even if you feel smoking relaxes you.

4 Try to relax before going to bed.

If you are in a relaxed mindset before you go to bed then you may find it easier to drift off.

5 Avoid vigorous exercise within two hours of bedtime.

Regular activity, such as a daily walk, can make you feel better both physically and mentally. But it's best to avoid intense exercise within two hours of bedtime, as the effects of the activity may make you less able to fall asleep.

6 Keep your bedroom calm and comfortable.

Try to reduce clutter and furniture and keep your bedroom tidy.

7 Avoid excessively hot or cold temperatures.

High room temperatures (24°C or higher) may disturb normal sleep and make you restless. Most people sleep better if their bedroom is cool. If possible, it's best to keep your bedroom temperature at around 16°C to 18°C.

8 Reduce noise and light in the bedroom.

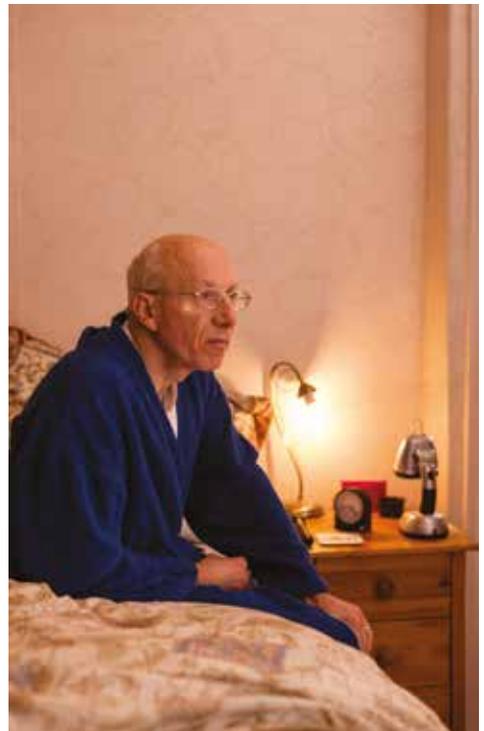
Light and noise can disturb sleep. Try to close windows, use ear plugs or move to a quieter room if noise is a problem. It's important to have a dark bedroom with curtains or blinds that keep out street lights or daylight. If this is a particular problem, try using an eye mask.

9 Keep your bedroom mainly for sleeping.

Ideally, bedrooms should be calm spaces for sleeping. Keep your bedroom for sleep, so your mind associates it with activities that lead to sleep. Try to avoid things like watching television or using laptops or tablets in bed.

10 Try to keep to a regular routine.

A regular routine is the key to better sleep. Try to stick to a regular pattern of times for bed, getting up, meals, exercise and other routine activities.



REDUCING TIME IN BED AWAKE

Reducing the amount of time you spend in bed awake can help strengthen or re-establish the 'triggers' for sleepiness.

If you are not sleeping, it may be tempting to stay in bed until you fall asleep. And it may help in the short term, but it's not effective in the long run. As you spend longer in bed, sleep becomes more 'broken' and restless, and the insomnia symptoms carry on.

Even if you don't think you're spending too much time in bed, there is no reason to stay in bed if you're not asleep.

Leave time to unwind

Try to leave at least an hour to unwind before you go to bed. Try to do any activity, such as reading, watching television, listening to music or talking, before you go to bed.

When it's time for bed try not to think too much about the day or your plans for tomorrow.

“ I find that getting out of bed when I can't sleep and only going back when I feel tired helps. I also take my daytime naps in bed, not the armchair. ”

Kendo, Parkinson's UK online forum user

Try to set aside time earlier in the evening to think about any issues. It may be helpful to write down any worries or concerns during this time and then plan how you'll deal with them at a later date. There isn't anything wrong with thinking about the things going on in your life and trying to solve problems, but try to put any concerns or negative thoughts to one side before you go to bed.

Go to bed only when sleepy

First, it's important to be aware of the difference between being tired and being sleepy. Tiredness is a feeling of exhaustion. But it does not always involve the need to sleep. Sleepiness means being ready to fall asleep. Signs of sleepiness may include yawning, having 'heavy' eyelids or sore eyes, or even feeling a little unsteady.

Waiting to be sleepy before going to bed can help you fall asleep faster. Going to bed too early can give you time to worry (about problems or being unable to fall asleep) and that, of course, can keep you awake.

If you don't fall asleep, try to get up. Lying in bed trying to get to sleep can make you feel anxious or frustrated. So try getting up after about 20 minutes, go to another room and do something quiet and calm, such as reading.

If you need help getting out of bed, talk to your partner or carer about what you're doing (if you have one). If they are prepared, and understand what is going on, it will be much easier for you both.

Go back to bed only when you feel sleepy. Try not to leave your bedroom only to fall asleep in a

chair or on the sofa as this doesn't help to build the link between your bed and sleep.

You may have to get up several times during the night if you can't fall asleep at bedtime or you wake during the night and can't get back to sleep. This can be difficult at first, but if you keep trying with this method your mind will soon link your bed and bedroom with getting to sleep quickly.

One common problem is going back to bed too soon after getting up. Some people think that if you stay up too long, you will never get back to sleep. In fact, the opposite is true: the longer you stay up, the quicker you fall asleep when you go back to bed.

You may not feel like leaving the comfort of your bed, particularly if you think you could be cold or bored while waiting to get sleepy. If this is the case, try keeping a warm blanket or dressing gown near your bed, have a comfortable place to sit in the house and keep things to do there. These shouldn't be so interesting that your mind becomes too active, but not so boring that you have no motivation to get up.

Some things you can try if you need to get up are:

- reading
- watching television
- listening to the radio
- doing a crossword puzzle
- knitting
- writing

Things to avoid:

- doing housework or cleaning
- taking a walk or exercising
- working on a computer or tablet
- worrying
- relaxing on the bed or in a chair

Use an alarm clock

Set an alarm clock and, if you are able to, get out of bed at roughly the same time every morning. Do this if it's a weekday or the weekend. It will help reset your body clock and restore your sleep-wake pattern.

It's common to 'lie in' to make up for lost sleep. This can help in the

short term, but it's best to stick to a regular routine.

Try not to nap during the day

For many people, napping during the day affects their quality of night-time sleep, and reduces the amount of deep sleep they get.

Some people with Parkinson's find they need a nap during the day. Certain medication, for example, can make people very sleepy. If this is the case, try to nap for a short time only, for around 20 minutes. This should not have too much of an impact on your night-time sleep. Set an alarm clock to wake you after 20 minutes if you're worried you'll sleep for longer.

Excessive daytime sleepiness is also a common feature of Parkinson's (see page 18 for more information). Following the tips in this booklet may help you overcome it.



SLEEP PROBLEMS LINKED WITH PARKINSON'S

Some causes of disturbed sleep are related to Parkinson's itself or to the medication used to treat it. This section looks at what some of the causes of disturbed sleep are and what can be done to help.

Parkinson's medication

You may find that your symptoms get worse as your Parkinson's medication starts to wear off. This may lead to stiffness, tremor, pain and being unable to move and turn in bed. When you take your next dose of medication, your symptoms may be less noticeable again.

If your medication is often wearing off during the night and is causing you problems, you may need to switch to a form that's delivered to your body continuously. Examples are skin patches, an apomorphine infusion or an intrajejunal levodopa infusion (a tube that pumps levodopa directly into your stomach).

The continuous delivery means you get constant treatment throughout the night. Speak to

“My husband has great difficulty turning over in bed, so we bought a special slip sheet. It has a satin panel, with just a few inches of cotton either side, to stop him from sliding out of the bed. It has proved invaluable.”

Jill, Parkinson's UK member

your specialist or Parkinson's nurse for more advice.

If changing your medication doesn't help, your GP, specialist or Parkinson's nurse may suggest referring you to a specialist hospital centre or sleep clinic for a sleep test. But it's important that you don't stop taking your medication before you talk to

a health professional, as this could be dangerous.

Find out more: see our booklet *Drug treatments for Parkinson's*.

Getting in and out of bed

Some people with Parkinson's may suffer from severe movement problems. This may mean that you need help from someone else to get in and out of bed. If you find getting in and out of bed difficult, there is a range of different aids available to help you. They can also benefit your carer, if you have one, as they will make the physical effort of helping you much easier.

If you don't have a carer but need help getting in and out of bed, then you can contact social services, to arrange for a night-time carer.

Turning over in bed

Turning over in bed can be difficult for people with Parkinson's because of rigidity. Changes to your medication may help to stop this, so speak to your specialist or Parkinson's nurse.

Using satin pyjamas or satin sheets may also help. The shiny material can help you to turn over, but try not to use satin sheets and satin pyjamas at the same time.

Together, they can increase the risk of sliding out of bed too quickly.

If you use satin sheets or panels, make sure there is an area of friction either at the end or sides of the bed, so you can get some grip. Your Parkinson's nurse or occupational therapist should be able to give you advice.

There is no specific bed or mattress recommended for people with Parkinson's. What is best for you depends on your individual needs and preferences. If you feel you need a new bed, mattress, or aids to help you get in and out of bed, speak to an occupational therapist. In some cases they may be able to provide bed aids, mattresses and specialist beds free of charge.

Find out more: see our information sheet *Occupational therapy and Parkinson's*.

You can also contact the Disabled Living Foundation for more information about aids and equipment (see page 25).

Akinetic pain

Akinetic pain is caused by a lack of movement and may interfere with your sleep.

The symptoms may include severe stiffness, pain in muscles and joints, headache and, sometimes, pain in your whole body. Speak to your GP, specialist or Parkinson's nurse to find out about ways they can help you to deal with this type of pain.

Nocturia

Nocturia is waking up at night with the urge to urinate, which can be a common problem for people with Parkinson's. If this urge happens during an 'off' period, some people find that they can't control their bladder and can't get to the toilet in time. There are other possible causes of nocturia, such as a bladder infection. Some medications can cause nocturia, for example some anti-depressants or medications for high blood pressure.

If you are experiencing this problem, speak to your GP, specialist or Parkinson's nurse to work out the cause of your nocturia. They can suggest ways to treat and manage the issue. You may also be referred to a continence advisor – a specialist nurse who assesses and manages incontinence.

If you are having problems sleeping because of an increased urge to pass urine at night, you can try the following:

- For bladder problems, it is important not to cut down too much on the amount of fluid you drink. That may leave you dehydrated and may make the bladder more irritable. But try and reduce the amount you drink in the evening and make sure you have been to the toilet before you get into bed.
- Avoid drinking alcohol or caffeine-containing drinks, such as coffee and tea, in the evening, and try to limit these during the day generally.
- Use bed protection, such as absorbent sheets and bed pads, just in case. Appliances such as handheld urinals or sheaths may also help you if you are having problems getting to the toilet.

Find out more: see our booklet *Looking after your bladder and bowels when you have Parkinson's*.

Low blood pressure or hypotension

A sudden or abnormal fall in your blood pressure when standing up quickly can make you feel light-headed. For example, when getting out of bed to go to the toilet.

If this happens, take care and move slowly. Speak to your health

professional about ways of managing low blood pressure.

Find out more: see our [information sheet *Low blood pressure and Parkinson's*](#).

Dystonia

Dystonia is involuntary contractions of the muscles in the toes, fingers, ankles or wrists that cause the body to go into spasm. It may, for example, cause the feet to turn inwards, or toes to curl downwards. It may feel like a painful cramp and it often occurs in the early morning, or at night as the effects of your Parkinson's medication wears off.

If you have any of these symptoms, your medication may need to be altered. Speak to your health professional for advice.

Find out more: see our [information sheets *Pain in Parkinson's and Muscle cramps and dystonia*](#).

Restless legs syndrome

Restless legs syndrome is an overwhelming desire to move your legs when you're awake. It happens mainly when you are resting, usually during the evening and at night. The symptoms include tingling, burning, itching or throbbing in your legs. You may also

“ If I'm experiencing restless legs, I drink tonic water during the day. I know that sounds strange, but it works for me. ”

hatknitter, Parkinson's UK online forum user

have pins and needles in your calf muscles and need to walk around to get relief. Contact with bedclothes may also feel uncomfortable.

Your healthcare professional may also advise you to increase your iron intake by taking a supplement or eating iron rich foods, such as dark green vegetables, prunes or raisins. Moderate or severe symptoms may be treated with medication.

To get some relief you could also try:

- massaging your legs
- relaxation exercises, yoga or t'ai chi, for example
- taking a warm bath in the evening

- applying a hot or cold compress to your legs
- walking and stretching

Rarely, your sleep may be disturbed because you have produced more dopamine than you need due to your Parkinson's medication.

The effect is similar to restless legs syndrome, but the abnormal involuntary movement (dyskinesia) is due to your medication.

If this is happening, your medication may need to be altered. Speak to your GP, specialist or Parkinson's nurse for more advice.

Periodic leg movements

'Jumping' of the legs, arms or body during sleep is not uncommon in Parkinson's. It's known as 'periodic leg (or limb) movements'. Some people get it with restless legs syndrome (see page 16), but it can happen on its own. It responds well to treatment with levodopa and dopamine agonists. Speak to your health professional for advice.

Find out more: see our information sheet *Restless legs syndrome and Parkinson's*.

Panic attacks, anxiety and depression

A panic attack is an overwhelming feeling of fear or terror that comes out of the blue. You may also experience physical symptoms such as sweating, a racing heart and shortness of breath.

Anxiety may be caused by excessive worry or stress. But it is also a symptom of Parkinson's. Anxiety and panic attacks can cause sleep disruption, so if you're affected by these, speak to your GP, specialist or Parkinson's nurse, as there are a number of ways that anxiety may be treated.

Depression is usually diagnosed when someone has feelings of extreme sadness for a long period of time. Symptoms may include insomnia (see page 6) and other sleep disorders, such as too much sleep. Sleep and night-time problems can be more common in people with Parkinson's who also have depression.

There are also a number of ways to treat depression. Speak to your health professional for advice.

Find out more: see our information sheets *Anxiety and Parkinson's* and *Depression and Parkinson's*.

Parasomnias

Parasomnias are abnormal movements or behaviours that happen when you are asleep. They also occur as you are waking up or when light sleep changes to deep sleep. They include nightmares and sleepwalking.

One problem is called 'rapid eye movement (REM) sleep behaviour disorder'. During REM sleep (commonly thought of as dream sleep) people with the disorder may move their arms and legs vigorously, possibly injuring themselves or bed-partners. They may also call out or scream in their sleep. This happens because people may be acting out a violent dream, which they may or may not be able to remember. REM sleep behaviour disorder is more common in people with Parkinson's and can be an early sign of Parkinson's before other symptoms develop.

Some people may also have hallucinations, wander, get agitated or talk loudly during sleep.

Night-time hallucinations can be a side effect of medication taken at night, or be due to other causes, such as an infection.

If you or your bed partner notice any unusual behaviour during

sleep, you should discuss this with your GP, specialist or Parkinson's nurse. In some cases you may be referred to a neurologist with a special interest in sleep disorders.

Find out more: see our [information sheet *Hallucinations and delusions in Parkinson's*](#).

Excessive daytime sleepiness

This is also known as daytime hypersomnolence. Drowsiness is a side effect of some Parkinson's drugs and this can sometimes be severe. Parkinson's medications can cause excessive daytime sleepiness or sudden onset of sleep. This may be more likely in people with later stage Parkinson's who are on multiple medications. It can also occur when increasing medication, particularly dopamine agonists.

Excessive feelings of sleepiness during the day can also happen if you're not getting enough sleep at night. The effect can cause people to fall asleep or doze off during normal waking hours.

In some cases, it can even lead to the sudden onset of sleep. This can be dangerous if you are doing certain things, such as driving or operating machinery. Medication may help, so speak to your GP, specialist or Parkinson's nurse.

Find out more: see our booklet *Driving and Parkinson's*.

Sleep apnoea

Sleep apnoea is a serious condition where a person momentarily stops breathing while asleep. This makes the person wake up, take a few breaths and go back to sleep again. The person has no memory of this happening, as it's so brief, but it disturbs their sleep.

Symptoms of possible sleep apnoea include loud snoring, choking noises while asleep or excessive daytime sleepiness.

If you or your bed partner notice any of the symptoms, you should seek treatment from a sleep specialist. Speak to your GP, specialist or Parkinson's nurse.





SLEEP MEDICATION

If you have long-term problems sleeping, it's possible that you are either taking, or have thought about taking, sleep medication such as sleeping tablets. In this section we look at the effects sleeping tablets can have on your sleep, becoming dependent on sleep medication and how to come off sleeping tablets.

When can sleeping tablets help?

Sleeping tablets can help in the short term (eg, up to three or four weeks) in some situations.

For example:

- if you have a short spell of insomnia due to severe stress, such as a bereavement, or after surgery
- if you have temporary insomnia caused by a change in environment or circumstances, such as being in hospital

Understanding the side effects of sleeping tablets

Sleeping tablets don't just affect sleep – they may also make you feel drowsy or 'heavy' in the morning, or anxious during the day.

They may interfere with your ability to perform some everyday tasks (like driving a car). The effects you may have will depend on the type of medication and dose taken. Older people are often given lower doses of sleeping tablets as they tend to be more sensitive to their effects.

Many people assume sleeping tablets will help them function normally the next day, but there is little scientific evidence for this. Rather than improving your alertness during the day, some sleeping tablets may actually make your memory and concentration worse.

For example, Benzodiazepines (a type of sleeping tablet) can affect your memory, particularly at night. People may wake up several

times during the night, but do not remember doing so in the morning.

Rebound insomnia

Sleeping tablets may cause rebound insomnia. This is when your insomnia symptoms briefly become much worse when you try to stop taking the sleeping tablets. You might also have feelings of anxiety.

Although rebound insomnia is always temporary (perhaps lasting two or three nights), the effects may last long enough to convince a person that they can't sleep without medication. So you may start taking sleep medication again, even after you've decided to stop. This, in turn, can lead to the long-term use of sleeping tablets.

Dependency on sleeping tablets

In general, prescription sleeping tablets are safe and effective. Dependence on these medicines does not develop over just a few nights, it develops gradually with long-term use.

Most people are given sleeping tablets by their GP during periods of illness, stress, when in hospital or when they can no longer cope with their insomnia symptoms. If you use sleeping tablets regularly your body slowly gets used to the

drug, and you develop what is called 'tolerance'. This means that the effects of the medication on you is less, so you have to increase the dose in order to get the same effect.

Eventually, sleeping tablets may no longer work, but if you try to stop taking the tablets you can't sleep because of rebound insomnia. You may come to depend on the medication long after it has stopped working.

Coming off sleeping tablets

When reducing or coming off sleeping tablets you will need help and support from your specialist or GP. They may advise you to reduce your sleeping tablets gradually (this is called 'tapering'), and can also help you with this. If you are regularly using sleeping tablets, never stop taking them without discussing it with your healthcare professional first.

What else could help?

Using sleeping tablets alone is rarely an effective way of dealing with long-lasting sleep problems as they do not treat the underlying reasons that are causing your insomnia.

Scientific studies have compared the effects of sleep medication with psychological treatments,

such as cognitive behavioural therapy (CBT).

Sleeping tablets produce faster results than self-help treatments. But psychological treatments also produce more permanent improvements that can have lasting benefits for your sleep.

Psychological treatments

These treatments may help you to manage your habits, routines and deal with insomnia. You may also be able to discuss your sleep problem with a psychological practitioner. Ask your GP about being referred.

Many treatments for insomnia look at making helpful changes to habits and feelings that may affect our sleep. These simple changes are:

- spend less time in bed awake
- go to bed only when you're sleepy
- keep to a regular bedtime and getting-up time
- avoid worrying in bed

Remember that Parkinson's varies from person to person. The symptoms you have and the rate it progresses are different for everyone. So there isn't a 'one size fits all' solution to sleep problems. But the ideas discussed here may offer some practical ways to help you get better sleep.





MORE INFORMATION AND SUPPORT

Battle Against Tranquillisers (BAT)

BAT works with people who take benzodiazepines. Their aim is to provide direct services to users and carers: through support groups, drop-ins, home visits, telephone helpline, website question and answer facility and specialist support for other agencies or workers.

Helpline **0844 826 9317** or

0117 9969 0303

www.bataid.org

Disabled Living Foundation

The Disabled Living Foundation provides information and advice on aids and equipment.

020 7289 6111

Helpline **0845 130 9177**

Textphone **020 7432 8009**

www.dlf.org.uk

Insomniacs

Insomniacs was formed to offer a reference point on how to overcome insomnia, sleeping problems and sleep disorders.

Their website has case studies and expert guidance on dealing with sleep issues.

www.insomniacs.co.uk

British Snoring and Sleep Apnoea Association

A not-for-profit organisation dedicated to helping snorers and their bed partners improve their sleep. Information on causes and treatments is available on their website or from telephone helpline advisers.

01737 245 638

www.britishsnoring.co.uk

Sleep Apnoea Trust

The Sleep Apnoea Trust aims to improve the lives of sleep apnoea patients, their partners and their families. They publish a regular newsletter, run a helpline and have information on sleep apnoea and lists of support groups.

0845 025 3500

www.sleep-apnoea-trust.org

Welsh Sleep Apnoea Society

They are members of the Sleep Apnoea Trust. The aim of their website is to give an insight on what sleep apnoea is, what the symptoms are, and where in Wales to turn to for help.

www.welshsas.org

NHS Choices

Has sections on treating insomnia and sleep hygiene.

www.nhs.uk

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their

specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **parkinsons.org.uk/nurses**

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**. We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our Parkinson's local advisors, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

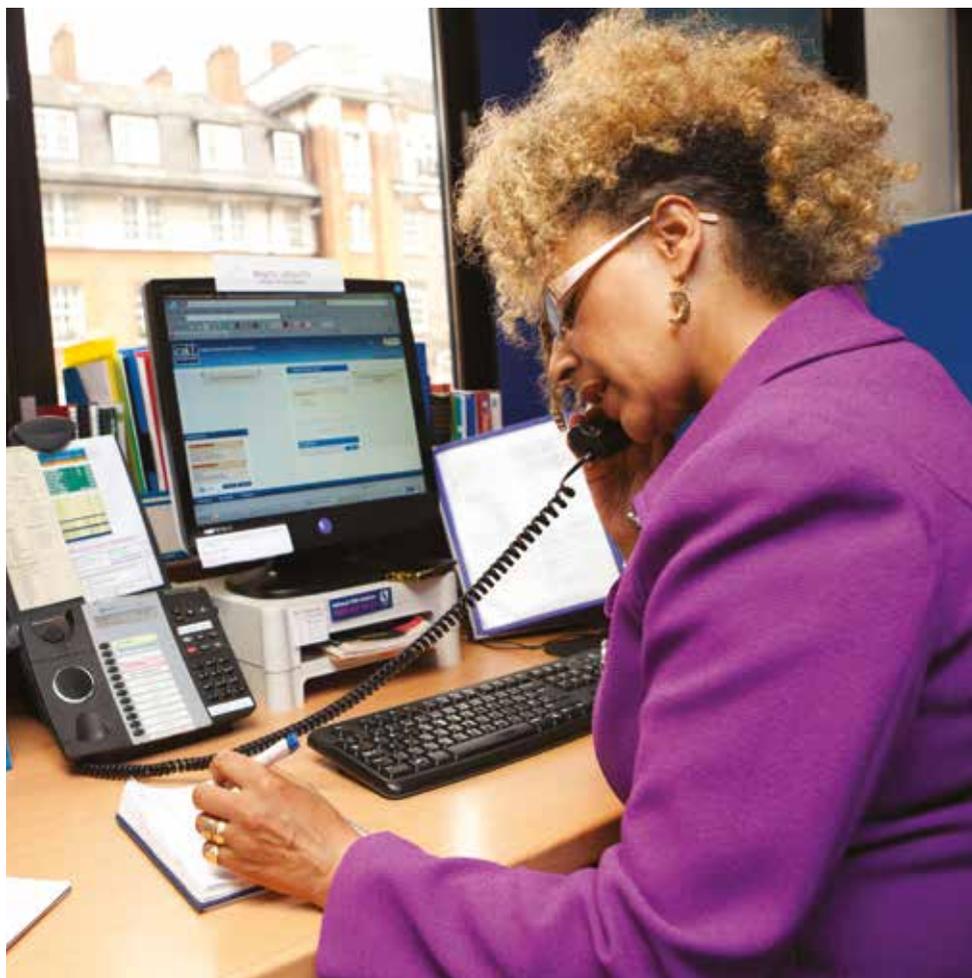
We also have a self-management programme for people with Parkinson's, partners and

carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit parkinsons.org.uk/selfmanagement

Our website parkinsons.org.uk has a lot of information about Parkinson's and everyday life with

the condition. You can also find details of your local support team and your nearest local group meeting at parkinsons.org.uk/localtoyou

You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.



Sleep and night-time problems (B070/2014)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
 - I care for someone with Parkinson's
 - I have a friend or family member with Parkinson's
 - I'm a professional working with people with Parkinson's
 - Other (please specify)
-
-

2. Where did you get this information from?

- GP
 - Specialist
 - Parkinson's nurse
 - Parkinson's UK local group
 - Parkinson's UK local adviser
 - Ordered directly from us
 - Call to the helpline
 - Other (please specify)
-
-

3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure



5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- | | |
|---|---|
| <input type="checkbox"/> It helped a lot | <input type="checkbox"/> It didn't help |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change | |

6. What is your ethnic background?*

- | | |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> White other |
| <input type="checkbox"/> Other (please specify) | |
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you?

- Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions



Thank you to everyone who contributed to or reviewed this booklet:

Sophie Molloy, Consultant Neurologist, Imperial College Healthcare NHS Trust, Charing Cross and Central Middlesex Hospitals

Paul Worth, Consultant Neurologist, Addenbrooke's Hospital, Cambridge

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: PKB070

Last updated October 2015. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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