# SLEEP AND NIGHT-TIME PROBLEMS IN PARKINSON'S



Sleep and night-time problems can be a symptom of 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 have with sleep, why they happen and what can help.

A note for family and carers

Sleep and night-time problems are very common among carers of people with Parkinson's too.

If you're 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 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're tired and need roughly the same amount of sleep each night.

Sleep patterns are set by your body clock. 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 you're 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 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. This is called good 'sleep hygiene'.

## How sleep can be disturbed

When routines and habits are disturbed, sleep is too. This often happens when you go away on holiday, or when you're ill. Usually these episodes don't last for more than a night or two, 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're 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'll 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

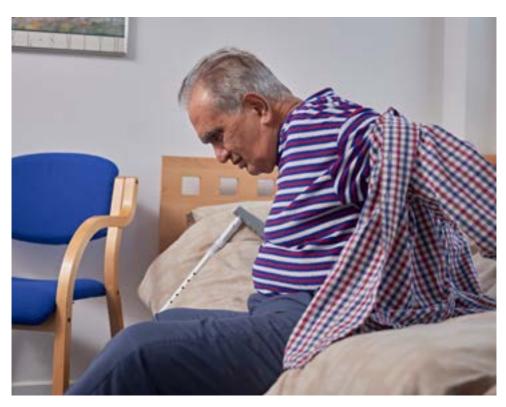
Insomnia is common in many long-term conditions. People with Parkinson's can be more prone to insomnia because of Parkinson's symptoms, such as tremor, stiffness, pain and restless legs syndrome, which can all disturb sleep.

Disturbed sleep can also be a direct symptom of Parkinson's, without these other symptoms.

(See the section 'Specific sleep problems linked with Parkinson's' to find out more.)

### Side effects of medication

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



## SLEEP PROBLEMS LINKED WITH PARKINSON'S

Disturbed sleep can be a direct symptom of Parkinson's, or it can be related to other symptoms of the condition, like tremor. It can also be linked to Parkinson's medication.

This section looks at some of the causes of disturbed sleep and what can be done to help.

#### Parkinson's medication

Parkinson's symptoms may be worse during an 'off' period, when your medication level is low and isn't working so well. This may lead to stiffness, tremor, pain and being unable to move and turn in bed. When you take your medication, your symptoms may be less noticeable because you are 'on' again.

If your medication often wears off during the night and causes you problems, you may need to switch to a form that's delivered to your body continuously. This could be through slow release levodopa, 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 your specialist or Parkinson's nurse to find out if any of these options might be suitable for you.

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 information on drug treatments for Parkinson's.

## Getting in and out of bed

Some people with Parkinson's suffer from severe movement problems. This may mean you need help 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. They can make the process less strenuous for your carer.

If you don't have a carer but need help getting in and out of bed, 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 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 that you can get some grip. Your Parkinson's nurse or occupational therapist should be able to give you advice.

There's no specific bed or mattress recommended for people with Parkinson's. What's 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 on occupational therapy and Parkinson's.

You can also contact the Disabled Living Foundation for more information about aids and equipment (see the end of this information to find out more).

## Akinetic pain

Akinetic pain is caused by a lack of movement. If this is a problem for you, it may interfere with your sleep. 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. It can be a common problem for people with Parkinson's. If this urge happens in an 'off' period, some people find 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 and medications for high blood pressure.

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

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

- For bladder problems, it's important not to cut down too much on the amount you drink overall. This may leave you dehydrated and may make your bladder more irritable. But try to reduce the amount you drink in the evening and make sure you go to the toilet before you go to bed.
- Avoid drinking alcohol or drinks containing caffeine, such as coffee and tea, in the evening, and try to limit these during the day too.
- 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're having problems getting to the toilet.
- Some medication may help with bladder hyperactivity. Your continence advisor may be able to help with this.

**Find out more:** see our information on 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 on 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 can feel like a painful cramp and it often occurs in the early morning, or at night as the effects of your Parkinson's medication wear off.

If you have any of these symptoms, your medication may need to be adjusted. Speak to your specialist or Parkinson's nurse for advice.

**Find out more:** see our information on 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're resting, usually in the evening and at night. Symptoms can include tingling, burning, itching and throbbing in your legs. You may also have pins and needles in your calf muscles and need to walk around to get relief.

To help with restless legs syndrome, your healthcare professional may advise you to increase your iron levels by taking a supplement or eating iron-rich foods, such as dark green vegetables, prunes or raisins. Medication can treat moderate or severe symptoms.

To get some relief you could also try:

- massaging your legs
- relaxation exercises, such as yoga or tai chi
- 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 movements (dyskinesias) are due to your medication.

If this happens, your medication may need to be adjusted. Speak to your specialist or Parkinson's nurse for advice.

## Periodic leg movements

'Jumping' of the legs, arms or body during sleep can by a symptom of Parkinson's. It's known as 'periodic leg (or limb) movements'. Some people get it with restless legs syndrome (see above), but it can also happen on its own. It can respond to treatment with levodopa and dopamine agonists.

**Find out more:** see our information on 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's 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 to treat anxiety.

Depression is usually diagnosed when someone has feelings of extreme sadness for a long period of time. Symptoms may include insomnia and other sleep disorders, such as too much sleep. There are also a number of ways to treat depression. Speak to your health professional for advice.

**Find out more:** see our information on anxiety and Parkinson's, and depression and Parkinson's.

#### **Parasomnias**

Parasomnias are abnormal movements or behaviours that happen when you're asleep. They also occur as you're 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 known as deep or dream sleep) people with the disorder may move their arms and legs vigorously, possibly injuring themselves or their bed partner. They 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 around, get agitated or talk loudly during sleep. Night-time hallucinations can be a side effect of medication, 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 on hallucinations and Parkinson's.

## **Excessive daytime sleepiness**

Drowsiness is a side effect of some Parkinson's drugs and this can sometimes be severe. This is also known as 'daytime hypersomnia'. Parkinson's medications can cause excessive daytime sleepiness or sudden onset of sleep. This may be more likely in people whose Parkinson's has progressed and 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. This 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're doing certain things, like driving or operating machinery.

Medication may help, so speak to your GP, specialist or Parkinson's nurse.

**Find out more:** see our information on driving and Parkinson's.

### Sleep apnoea

Sleep apnoea is a condition where a person momentarily stops breathing while asleep. This makes them 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 sleep apnoea include loud snoring, choking noises while asleep and 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.

## TREATING SLEEP PROBLEMS IN PEOPLE WITH PARKINSON'S

## Improving sleep hygiene

If you're having trouble sleeping, there are simple things you can do that may help. One of the first is to improve your 'sleep hygiene'. This means dealing with the simple things that help or stop you sleeping.

Here are 10 sleep hygiene 'rules':

#### 1. Don't have caffeine before 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 to get to sleep and make sleep lighter and more restless. It's also important to limit the total amount of caffeine you take during the day too – or eliminate it altogether.

## 2. Avoid eating a big meal or drinking alcoholic drinks four to six hours before bedtime.

Alcohol can make you feel sleepy. But as its effects wear off it can have the opposite effect and make you feel restless. This can mean you wake up during the night. Another effect of drinking alcohol at night is nocturia – the need to get up and go to the toilet – which again will 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're in a relaxed mindset before you go to bed you may find it easier to drift off.

## 5. Avoid vigorous exercise within four hours of bedtime.

Increasing exercise can help you manage your Parkinson's symptoms, but it's best to avoid vigorous activity within four hours of bedtime. This is because 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 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 and daylight. If light is a particular problem, try using an eye mask. Also, don't watch television or use devices right before going to bed – the bright light can make you feel more awake.

## 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 computers 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.

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. Activities such as reading, watching television, listening to music or talking may help.

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

## Only go to bed when you're 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 doesn't 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, which 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, and what help you need from them, to make it 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'll 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. For example you could try reading, watching television or doing a crossword puzzle. Try to avoid things like housework or exercise.

#### Use an alarm clock

Set an alarm clock and, if possible, get out of bed at about the same time every morning, including weekends. This 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, perhaps around 20 minutes. This shouldn't have 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.



## TREATMENTS FOR SLEEP PROBLEMS

If you have long-term problems sleeping, it's possible that you're 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.

## Sleeping tablets

Sleeping tablets can help in the short term (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

However, they are rarely a longlasting solution to sleep problems in people with Parkinson's.

## Understanding the side effects of sleeping tablets

Sleeping tablets don't just affect sleep – they may also make you feel drowsy the next day.

They may interfere with your ability to perform some everyday tasks (like driving a car). Any effects 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.

Rather than improving your alertness during the day, some sleeping tablets may actually make your memory and concentration worse.

#### 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, 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 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 the medication has less effect on you, so you have to increase the dose 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'll need support from your specialist or GP. They may advise you to reduce your sleeping tablets gradually (this is called 'tapering'), and they can also help you with this. If you're using sleeping tablets regularly, never stop taking them without discussing it with your health professionals first.

## **Psychological treatments**

Using sleeping tablets alone is rarely an effective way of dealing with long-lasting sleep problems as they don't treat the underlying problems 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 psychological treatments. But psychological treatments also produce more permanent improvements that can have lasting benefits for your sleep.

These treatments may help you to

manage your habits, routines and to 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.

Simple changes can include:

- spending less time in bed awake
- going to bed only when you're sleepy

- keeping to a regular bedtime and getting-up time
- avoiding 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 in this information may offer some practical ways to help you get better sleep.



## MORE INFORMATION AND SUPPORT

#### 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. There's information on causes and treatments on their website and they also have a helpline.

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 038 0060 www.sleep-apnoea-trust.org

#### 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 act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can tell you about 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** 

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

Our website has information about your local support team and how to contact them at parkinsons.org.uk/localtoyou

You can find details of our local groups and your nearest meeting at parkinsons.org.uk/localgroups

You can also visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

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

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

All of the photographs in this booklet feature either people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's or Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

### 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/informationsupport

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at parkinsons.org.uk/ orderingresources 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

## Sleep and night-time problems in Parkinson's (PKB070/2019)

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!

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2. Where did you get this inform  GP Parkinson's nurse Parkinson's UK local adviser Call to the helpline Other (please specify)	ation from?  Specialist Parkinson's UK local group Ordered directly from us
<ul><li>3. Has it answered all your quest</li><li>Yes, completely</li><li>Yes, mostly</li><li>Partly</li></ul>	ions?  Not sure  Not at all
<ul><li>4. How easy was it to understand</li><li>Very easy</li><li>Easy</li></ul>	d?  Quite difficult  Very difficult

Not sure			
5. Has it helped you manage your condition better, or make			
choices that have improved your life in some way?			
☐ It helped a lot ☐ It didn't help			
☐ It helped a little ☐ It made things worse			
☐ No change			
6. What is your ethnic background?*			
Asian or Asian British Mixed			
☐ Black or Black British ☐ White British			
Chinese White other			
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.			
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To find out more, read our privacy policy at <a href="mailto:parkinsons.org.uk/termsandconditions">parkinsons.org.uk/termsandconditions</a>



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 March 2019. 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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