

Living Well with a Long-Term Health Condition:

4. Your Sleep

Why this leaflet?

This resource is intended for people who are living with, or have recently been diagnosed with, a long-term health condition. Unfortunately, people who have long-term health conditions are more likely to experience insomnia, poor quality sleep and fatigue. This is more likely if your condition is painful or uncomfortable, or you experience other symptoms or find you need to go to the toilet at night. These sleep problems can all have a big impact on day-to-day life. It may affect your mood, your activities and your outlook on life, as well as making you feel worse physically.

This leaflet contains some ideas that might help you to better understand your sleep problem and take steps to improve your sleep. You may need to adapt things slightly to your own health needs. If you have concerns about anything or how to adapt things to your own particular needs, please ask your GP or your health care professional.

The full range of IMPARTS booklets can be found at:

<https://imparts.org/resources-self-help/>

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Understanding sleep

How much do I need?

Most people are eager to know how much sleep they should be having, or how much sleep is 'normal'. The Sleep Council suggests that working-age adults usually need about 7-9 hours of continuous sleep every night. Older people normally require slightly less, 6-8 hours. However, people vary so much that some people can even survive on as little as 4 hours per night, whereas for others 10 hours or more is needed. The amount of sleep you need can vary with age, the amount of activity you are doing, your daily routine and with changes in your health. Some people can also

find that they feel better by taking an extra (shorter) period of sleep at another time of day and, provided this is part of a routine and does not disrupt night-time sleep.

The following resources on this topic might be helpful:

- Insomnia - NHS (www.nhs.uk/conditions/insomnia)
- Sleep problems - Every Mind Matters - NHS (www.nhs.uk/every-mind-matters/mental-health-issues/sleep)
- [Sleeping Problems.pdf](http://SleepingProblems.pdf)
(ntw.nhs.uk/selfhelp/leaflets/Sleeping%20Problems.pdf)

The sleep cycle

Unfortunately, there is no on-off switch for sleep. Instead, there are five stages of sleep that range from drowsiness to very deep sleep. Each night, we move through the various stages of sleep several times. It is quite normal to wake up briefly during the night, although you might not always remember it. Waking up during the night becomes more common with age and is a normal change in the sleep cycle.

Sleep problems and insomnia

Everyone experiences difficulty sleeping for short periods from time to time. This is normal and can be due to several factors like changes in routine or habits, short-term worries/stress and shorter-term health problems. There may be no obvious cause. Usually, sleep will return to a normal pattern eventually.

However, when sleep difficulties keep going with no improvement you may be experiencing a sleep problem, sometimes called insomnia. People living with long-term health conditions may be more vulnerable to this.

There is no clear-cut answer as to why some people with short-term sleep problems go on to develop insomnia and others do not, but it is probably a mix of physical symptoms together with certain thoughts, feelings, and habits which keep sleep problems going.

Types of sleep problems

- Trouble falling asleep.
- Trouble staying asleep.
- Waking up very early in the morning.
- Poor quality sleep and not feeling rested when you wake up.

Causes of sleep problems

Physical causes

Physical health problems can often disrupt sleep. For example, you may experience pain, unpleasant physical symptoms related to your health condition or the side effects of medications. All of these could play a part in disrupting your sleep.

Your feelings

Being unwell with a serious or long-term health condition can be a very worrying and stressful experience and it is normal to feel anxious and apprehensive at times. You might worry about how your condition affects your life now, or how it might affect you in the future. This uncertainty can lead to stress and anxiety.

Stress and anxiety can cause you to feel both emotionally and physically uneasy and tense. Being 'on edge' can also get in the way of the process of falling asleep, which relies on becoming more and more relaxed until you drift off to sleep. Feeling low in mood can also make it hard to sleep well.

The following leaflets in this series might help you further on this topic:

- [Managing Anxiety and Worry](#)
- [Coping with Low Mood and Depression](#)

Your thoughts

Worrying thoughts often go hand in hand with feeling uneasy or anxious. People who have health problems may have lots of worries. For example, you might think about the negative ways your health condition affects your life. You may also think about the future and about whether your condition will change, causing you more problems. Worries like these, and a spiral of unhelpful thoughts, can often feel much worse at night when it is dark, quiet and there are no distractions. Having these thoughts going round and round in your mind at bedtime can get in the way of sleep by keeping you alert.

Your environment and routine

Your home environment is a very important aspect of getting good sleep. Sleep problems can persist if your room is too bright, too hot, too noisy or too cluttered. Electronic devices such as phones, tablets and TVs on in the room where you are sleeping may also contribute to sleep problems. There is research suggesting that light from the 'blue' screens of electronic devices can disrupt sleep. Even though these distractions may help you manage difficult thoughts and feelings in the short term, they may be keeping your sleep problem going, making you feel worse physically and mentally in the longer term.

Sleeping in hospital

If you have spent any nights in hospital, you may have been trying to sleep in a noisy, unfamiliar environment. There may be a completely different routine from what you are used to. You may also have tried to catch up by sleeping or dozing during the day. This kind of disruptive environment and routine can easily affect your sleep cycle. Your sleep may continue to be disturbed even after you have left the hospital. It may take a while for your normal sleep routine to re-establish itself.

Effects of sleep problems

Poor sleep and insomnia can affect you in a number of ways.

You might feel:

- Tired, lacking energy, groggy, sleepy in the daytime.
- Snappy, irritable, short-tempered.
- More on edge, anxious, jumpy.
- As if you can't be bothered, withdrawn, low in mood.
- Physically or mentally restless.

You might notice that you:

- Can't concentrate, are distractible, have trouble making decisions.
- Are worrying about things more.
- Don't feel like doing much, take naps during day.
- Start to dread bedtime.
- Worry about the negative effects of not sleeping

What keeps sleep problems going

There are a number of habits and thought patterns that can keep sleep problems going. Often these habits can creep up on us before we realise that they have become a problem.

Habits and behaviours

There are numerous habits and behaviours that might influence your sleep problems. These include:

- Drinking too much caffeine, especially in the evenings. English breakfast tea, green tea, coffee and hot chocolate all contain caffeine. Some over-the-counter pain relief and cold and flu remedies contain caffeine so make sure to read the packets carefully.
- Using alcohol to help you fall asleep. You may fall asleep more quickly, but the quality of your sleep will be worse.
- Eating a big meal within an hour or so of going to bed or not eating enough so you are hungry

- Napping during the day. A nap can be fine if it is part of your routine, and you still sleep well at night. However, if napping is affecting your sleep at night, you might need to think about changing the routine. The most important thing is to have a routine so your body gets used to what to expect. Lots of naps and very little routine may begin to affect your sleep at night.
- Doing too little exercise or activity during the day.
- Doing too much strenuous exercise near bedtime.
- Doing mentally exciting things like watching thrillers, horror films or reading an exciting book
- ‘Clock watching’. This is checking the time repeatedly when you are having difficulty falling asleep or when you wake up in the night. This is usually unhelpful, particularly if it triggers thoughts like “Only three hours left until the alarm goes and I am still awake!” (Read on to understand how thoughts keep sleep problems going).

Your thoughts

Lots of thoughts running through the mind at bedtime can make it really difficult to switch off, clear the mind and relax. The kind of thoughts that can make falling asleep difficult include:

- Worries about health, the future, money worries etc.
- Active planning and problem solving at bedtime
- Mentally chewing over negative things (this is called “rumination”)
- Unhelpful worries about how poor sleep will affect you negatively the next day.

Getting caught up in unhelpful thinking about sleep is very common when you experience sleep problems. This can often keep sleep problems going by making you feel worried and anxious about the effects of poor sleep. If these thoughts are extreme, they can cause significant distress, however these kinds of negative thoughts are rarely accurate. See if you recognise anything below.

Unhelpful thoughts

Predicting the worst	“Because I haven’t slept well, I won’t be able to function at all tomorrow. I may not manage my work and may even lose my job.”
Should, must and ought	“I must get eight hours of unbroken sleep.”
Generalising	“I didn’t sleep last night and the night before. That means I must have permanent insomnia.”
Jumping to conclusions	“I feel awful after a bad night’s sleep. I feel so bad it must be a sign my condition is getting much worse.”

If people have and believe these unhelpful thoughts, they can become anxious and upset about their sleep difficulties. However, not all thoughts are facts and what we worry might happen because of poor sleep often does not happen. The ‘overcoming

sleep problems' section of this leaflet suggests how to challenge unhelpful thoughts which may not even be true.

Your emotions

- Feeling very stressed and anxious about sleep or about other things can keep sleep problems going by getting in the way of the process of normally falling asleep.
- Feeling down in the dumps, low or depressed can also make it hard to fall asleep. It can make you feel helpless to do anything to get your sleep back on track.

How your body feels

- Aches, pains, unpleasant symptoms, and physical tension related to your health condition can contribute to sleep difficulties.
- Inactivity can also cause some of these symptoms, particularly if you sit or lie in one position for a long time without moving.
- Doing much more activity than you are used to can lead to aches and pains afterward. If you are returning to exercise, try to increase your activity gradually and seek health care advice if you are making big changes to your activity levels.
- Anxiety can also add to physical tension and discomfort.

Overcoming sleep problems

Take care of yourself

Try to eat a well-balanced diet spread across the day. This may help your body fight off infections and recover if you have been unwell. It will also prevent you from being too full or too hungry to fall asleep at night.

Try to be as active as you can and do regular exercise. As well as helping you feel tired and sleepy by bedtime, exercise is also helpful for managing the tension and fatigue associated with anxiety and low mood. Think of an activity that is manageable for you and which you might enjoy. Then try to pace yourself, not doing too much or too little.

Get some light

Expose yourself to some light, either sunlight or bright artificial light, during the day. This is one way to reset the body's sleep-wake cycle if it has been disrupted.

Good sleep habits

Good sleep habits, or 'sleep hygiene,' are things you can do to improve your sleep. Here are some suggestions of things you can try out until you find the ones that work for you. Be patient. It can take a few weeks for new habits to establish themselves.

- Go to bed at approximately the same time every night. Once you are in a good routine it won't matter if you have the occasional late night or lie in, but it is the best way to try and set a good sleep pattern.
- Get up at roughly the same time every day regardless of how you have slept.
- Wind down with relaxing activities before bed, e.g., listen to gentle music or take a bath.
- Make your bedroom comfortable and somewhere you want to be. Try to make sure it is dark and well-ventilated. Think about getting black-out curtains if your bedroom is very light at night.
- Try to ensure your bedroom is as quiet as possible. If you are bothered by noise, try earplugs.
- If space allows, keep the bedroom for sleep. This can help to strengthen the link between sleep and bed and weaken the unhelpful link between bed and wakefulness.
- If you are very restless or wakeful during the night, try getting up and walking or sitting out of the bedroom for a little while. Again, this will help you associate the bedroom with sleep only.
- If you have a habit of worrying what you need to remember for the next day keep a pad of paper by the bed and write it down. That way it will be there to remind you in the morning (see the section of Putting the Day to Rest).
- Avoid caffeine, especially in the second half of the day.
- Avoid nightcaps (i.e., alcoholic drinks just before bed).
- Avoid napping during the day unless it is part of a clear routine, or you are so tired you cannot function.
- Avoid physically or mentally stimulating activities before bed.
- Avoid using electronic screens immediately before bed or at night.

Learn to relax

Learning how to relax your mind and body can help you get ready for sleep. You can try out different things until you find one (or more!) that works for you. For example:

- Listen to relaxing music or 'white noise' like the sound of waves crashing. You can download free 'White Noise Apps' to your smart phone, use Google to find audio files to download to your PC or
- There are many apps available for helping you fall asleep. If you are using an app at bedtime, try not to be distracted and use your phone for other things.
- Spend five minutes focusing your attention on your breath.
- Try using meditation practices
- Try using 'mindfulness'. Again, there are many books and apps available.

- Gently tense and relax different muscle groups in your body until your body feels physically relaxed. (of course, skip any areas where you have discomfort).
- Make sure you allow time to relax during the day, so the tension has not built up so much that it is hard to switch off at night.

Keep a sleep diary

It might help to keep a diary of your sleep for a few weeks. Try recording the following:

- When you went to bed.
- How long it took you to fall asleep.
- How many times you woke up during the night.
- How many hours of sleep you believe you got.
- What time you get up in the morning.

Try doing this in the mornings soon after you wake up. Of course, it doesn't matter if you don't do it exactly, but the best guess will help you to build up an idea of your sleep pattern and any sleep problem(s). Also take note of what was going on that day, how you were feeling, and record anything you tried to help you sleep. You might notice patterns to your week – are there, for example, day(s) of the week when you regularly sleep well or poorly. After a few weeks, you can then review the diary and notice what might help and hinder your sleep.

Put the day to rest

Earlier, we discussed how worries, concerns, planning and problem solving can all get in the way of falling asleep by keeping you alert. One way to overcome this is to 'put the day to rest' before you go to bed.

Get a notebook and write down:

- Your main worries and concerns. Take them out of your head and put them onto the page. If there is something you could do about these concerns, jot down a few ideas about how to overcome and decide to return to these solutions the next day
- Your 'to do' list for the next day or any other planning you need to do
- Any reflections about the day and how it went. For example, what was your favourite moment of the day? These reflections could be both positive and negative

Now put the notebook away. If you notice your mind wandering to the list, remind yourself that you can give it your attention again in the morning.

Challenge your thoughts

Certain thoughts, beliefs and predictions about a bad night's sleep can turn a few nights of bad sleep into insomnia. For example, people with sleep problems sometimes overestimate the negative effects of a bad night's sleep. This is unhelpful because it increases worry and anxiety which makes sleeping even more difficult. To challenge some of these predictions, try to ask yourself the following questions.

For example, take the thought like "If I don't sleep well, I won't be able to function at all the next day" and ask yourself the following questions:

- "How do I know this is true?"

Ask yourself, has this ever happened or, instead, is it something you worry about? You may feel tired, but has your absolute worst fear ever happened? (For example, losing your job due to yawning).

- "Is there any evidence against this thought?"

It is true that you may not be at your best and you may not get as much done as you planned when you are feeling fatigued. This is normal. However, there were at least sometimes during the day when you managed quite well and achieved things despite a poor night's sleep. Try to focus on these examples.

- "Is there any other way of thinking about this?"

You might be able to come up with an alternative thought. For example, you might try saying to yourself "If I don't sleep well, I'll probably feel pretty rough tomorrow. That won't be great, but I've handled a day like that before and I can cope if it happens again."

You might find that a balanced thought like this helps to reduce your anxiety and may, over time, even help you get off to sleep.

- "What would I say to a friend?"

Often, we are much harder on ourselves than we would ever be on other people. Ask yourself what you would say to a friend who was struggling with day-to-day activities due to poor sleep. Would you say 'Pull your socks up and get on with it' or 'Just give up! What's the point?' Probably not.

Instead, would you reassure them that everyone has bad patches with their sleep from time to time, encourage them to prioritise a couple of important things to do and then let themselves off the hook, especially if their standards were high to begin with.

Managing fatigue

One of the most unpleasant side-effects of poor sleep is daytime fatigue. Fatigue is also a common part of many health conditions. When people have fatigue for weeks or months, it is common to get into a habit of doing lots of activity when you have a 'good day' (i.e., less fatigue) but hardly anything the next day because you are exhausted, sometimes called a 'bad day'. This cycle of overdoing it and underdoing, can lead to more fatigue. This is because the number of 'bad days' begin to start to outnumber the 'good days' making it difficult to stay active and healthy and more likely to fatigue easily.

You can break this 'boom and bust' cycle by trying to do a similar amount of activity each day regardless of how tired you feel. This means doing a bit less than usual on 'good day' and a bit more than usual on a 'bad day'. Over time, this builds up your fitness and helps to combat fatigue.

Try paying attention a different way

Being awake when you want to be asleep is very frustrating and this can lead to more wakefulness. As an alternative, try taking a curious and non-judgemental attitude towards whatever you are experiencing in the 'here and now', rather than letting your attention rest on the past or the future. This is sometimes called 'mindfulness.' Try these simple steps:

1. **Focus first on your breath.** Pay attention to the natural rhythm of your breath. Notice the rise and fall of your chest and stomach. Notice how the breath feels coming in and out of your nose. Pay attention to any changes in your breath. Don't be concerned if you notice your mind has wandered off. This is normal. Just gently bring it back to the breath.
2. **You can focus on any sensation or experience, not just the breath.** You could experiment with paying attention to the experience of being in bed. Notice the texture of your bedding, the warmth or coolness of different parts of your body, any noises you can hear like the rustle of sheets as you move.
3. **Try focussing on the five senses:** touch, taste, smell, hearing and sight. This can be a very helpful way of experiencing the 'here and now' and is a way of focussing differently on your feelings and restlessness. For example, focus your attention on the experience when you are wakeful. Notice things related to all the senses. Does this become more or less intense as you observe it over time? Do you feel it in different parts of your body? Does it change from jittery, to alert, to calm, to sleepy?

Being mindful of your experiences is a different way of paying attention and it takes a bit of practice. There are many good books and CDs about mindfulness and about how to apply this to your everyday life if you think this approach might be helpful for you and you would like to learn more.

Managing low mood

Sleep problems can lead to low mood, particularly if you have experienced low mood or depression in the past. There are some things you can try to lift your mood:

- Make time for doing things you enjoy and find pleasurable.
- Talk to someone you trust about how you are feeling. You can ask them just to listen or suggest how they can support you.
- Try to keep seeing people and doing your daily activities. Sometimes it might seem easier to withdraw and keep yourself to yourself, but this can make you feel worse in the long term.
- Focus on signs of improvement and achievements. Celebrate any changes in the right direction, however small. Try this instead of focusing on the less good things.
- If you notice you have negative thoughts, try using the 'thought challenging' suggestions to question them.
- If you are concerned that you may be experiencing depression that is not improving despite your best efforts, see your GP or healthcare professional who can discuss the options for support and treatment with you. There are also other services you can refer to: your local Talking Therapies service (Formerly IAPT - Improving Access to Psychological Therapy) may be able to help – you can self-refer to this.

Next steps

- Plan a time to use the ideas in this leaflet.
- Share the ideas with someone who can support you.
- If you have tried the ideas in this leaflet and you have not seen any improvements, talk to your healthcare professional about getting further support.

Kings Patient Advice and Liaison Service (PALS)

This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Their website can be found here: PALS – King’s College Hospital NHS Foundation Trust (kch.nhs.uk/patientsvisitors/help-and-support/pals).

Tel: 020 3299 3601 Fax: 020 3299 3626 Email: kch-tr.pals@nhs.net

Providing feedback

We welcome your feedback on this series of leaflets, please use the QR code or the link below to access a short survey. <https://forms.office.com/e/R86s27ggfa>



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