
Managing side-effects – Sleep problems

Some women experience one or more side-effects from taking hormone therapy, others do not. There is no way to predict who will experience side-effects, and who won't.

It's important not to assume that any unwanted effect you might be experiencing after breast cancer is solely due to hormone therapy. There are a range of possible causes, such as other treatments (e.g. chemotherapy) or medicines. The normal ageing process and the menopause can also account for some symptoms women can experience. So stopping hormone therapy would not necessarily mean symptoms would disappear.

Side-effects can vary in level of intensity and this can change over time; a side-effect may become less frequent or intense or disappear altogether as time goes on. Again, it's not possible to predict whether this will happen to you. **Rather than looking at all the side effects now, you may find it helpful to come back to this page if and when your side effects change.**

The good news is that **there are many things that can help with side-effects.** This section includes information about some of the most common side-effects women can experience, and a range of tips and hints for managing these.

This section includes information on the following topics:

- General hints and tips to help sleep
- Healthy living to improve sleep
- Changing the way you think and feel about sleep problems
- Asking your breast cancer team or GP for help
- Further help and support

Sleep problems

Many women find they struggle with their sleep after a diagnosis and treatment for breast cancer. This is also known as insomnia.

Many women also struggle with sleep problems when they get older, even without taking hormone therapy so **it can be hard to work out what is causing the sleep problems**, and often it could be due to multiple things.

Insomnia is a term for all kinds of problems with sleep, including:

- difficulty getting to sleep, staying asleep, or waking too early
- difficulty sleeping despite good conditions for sleep.

Insomnia can lead to waking up feeling unrefreshed and/or daytime activities being affected by lack of sleep - for example, having problems concentrating at work, falling asleep during the day or low mood.

"I struggle to get a good night's sleep. My pattern has completely changed and although I have no trouble getting to sleep, I will wake in the early hours and then be up for a number of hours or sometimes never do manage to get back to sleep. The only good side of this is that I am a crafter, and have had some of my best ideas in those early hours!"

Roseanna, Breast Cancer Patient, Age 61

Having one or a few nights of poor sleep is unlikely to have any effect on you other than leaving you feeling tired the next day. But longer periods of sleeplessness, or disrupted sleep (e.g., three months or more) need greater attention and can lead to concentration problems, difficulty making decisions, irritability, and sometimes anxiety and depression.

General hints and tips to help sleep

You may find the following suggestions helpful for sleep.

Manage any physical symptoms

Try to make sure that any physical symptoms you have (such as pain) are adequately managed at night.

These, if not managed, can disrupt your sleep and make you feel frustrated and stressed.

You may find it helpful to:

- take over-the-counter or prescribed painkillers before you plan to go to sleep
- try out other techniques that can be used to soothe or relieve symptoms around bedtime. For example, relaxation exercises, massage or a warm bath (if you can tolerate it) could help relieve symptoms and help you to wind down and feel sleepy
- if you think your symptom (e.g., joint pain) is linked to your hormone therapy, try taking your hormone therapy at a different time during the day.

Create the right environment for sleep

Making sure that your bedroom is the best environment possible for a good night's sleep can be really helpful.

Try to keep your bedroom only for sleeping. Any activities other than sleep or intimacy that take place in the bedroom prior to bedtime can directly disrupt your sleep, and how sleep and sleepiness are associated with your bed and bedroom.

Eating, watching TV, doing work in bed, or using a laptop or mobile phone can make you feel more stressed and/or awake. This can make you link your bedroom less to sleep and make sleep problems worse. This does not include sex or intimacy, which can have sleep promoting effects.

How can I make sure my bedroom is the right environment for a good night's sleep?

Consider the following questions to see if there is anything you could change about your sleep environment:

- Is your bedroom quiet? If bedroom noise is a problem for you, you could try using ear plugs, listening to 'white noise' which is a constant, monotonous and meaningless sound like a waterfall (you can search for 'white noise' videos on the internet for free or buy a 'white noise' device), or add insulation for your windows.
- Is your bedroom pitch black? Does sunlight come in at dawn? Consider installing black-out blinds, putting up heavy curtains (or adding removable linings to your curtains in the summer) or using an eye mask to block out light.
- Is your bedside clock facing you? If you are trying to fall asleep or lying awake in the night, watching the clock often can increase stress and makes it harder to sleep. Try putting the clock under the bed or turn it away from you so you cannot see the time in the middle of the night.

- Is there any artificial light in your bedroom? Consider removing electronic devices from your bedroom. If you need the bathroom at night, try a night light (instead of turning on a lamp).
- Is your bedroom cool enough? Ideally it is best to keep your bedroom cool at night (16-18°C or 61-64°F). You could open the window. Try a thinner quilt and layer on blankets if you need them.
- Is your bed supportive and comfortable? It may be worth considering whether you need new pillows or a new mattress. Pillows should ideally be replaced every 1-3 years, and mattresses every 7-10 years. If they are too old, they can be uncomfortable and disrupt sleep.
- Are there any scents you could introduce? Lavender is associated with a decreased heart rate and blood pressure and feeling less stressed and anxious, which encourage sleep. You may find a lavender scented diffuser or pillow spray helpful.

Create a good sleep routine

Having a soothing and relaxing pre-sleep routine can really help you to get a good night's sleep – this can help you ease the transition from feeling awake, to sleepiness and then to sleep.

- **Try to resolve worries and problems before bed.** If you find you worry around bedtime, try setting up some 'worry time' earlier in the day or evening. Try making a list of the things you worry about and think about possible solutions to try the next day. If you wake in the night and are still worrying, you can get up, make a few notes on your list and forget about it, reminding yourself that you have dealt with your thoughts as best as you can.
- **Create a 'buffer zone' to help put the day to sleep.** Choose a relaxing activity to do outside of the bedroom before you go to bed such as preparing the next day's lunch or dinner, listening to music, stretching to relax your muscles, reading a book, watching TV, or using relaxation, imagery or breathing techniques.
- **Go to bed only when you are truly sleepy.** Going to bed before you are truly sleepy (not just tired) can make it hard to fall asleep. If you are in bed and don't feel sleepy you may find it helps to get up and leave the bedroom and return to bed only when you truly feel sleepy again. You should repeat this process as many times as necessary during the night.

"I struggle with sleeping a full night and often find my mind racing worrying that every ache and pain is the cancer returning. When I can't get off to sleep, I try a breathing exercise which I have found very helpful. It's called the 4-7-8

breathing technique and is very simple to do. 9 times out of 10 this works for me"

Emma, Breast Cancer Patient, Age 58

"Don't fight insomnia. Some days I wake up as if I've got jet lag but I carry on and grab 30 mins or an hours nap at some point in the day. I don't bother fighting the insomnia in the night, I read a book, watch tv, whatever - just try and catch up a bit of sleep at some point. That said, it's possibly easier for me because I've never needed a lot of sleep, six or seven hours is more than enough"

Sian, Breast Cancer Patient, Age 58

- **Aim to wake up at the same time each day.** No matter what time you go to bed, or how well (or badly!) you have slept, if you try to wake at a similar time each day (using an alarm clock) this can help to train your body, and 'internal clock', to expect wakefulness at a certain time each morning. This promotes stable patterns of sleep and wakefulness.
- **Aim for short naps early in the day if you are tired.** Long or multiple naps during the day, particularly in the evening, can make it harder to fall or stay asleep. Short naps (less than 30 minutes) generally help with alertness and mood, and one or two short naps taken early in the day interfere less with night-time sleep. You should delay your bedtime by the amount of time that you nap e.g., if you nap for 30 minutes in the day, you should go to bed 30 minutes later than usual.
- **Get more sunlight during the day.** Daylight enhances alertness and can help raise the levels of melatonin during the night, which leads to better sleep. Before you start your day, you may find it helps to spend at least 15 minutes in the light and get some sunlight during the day. For example, this could be a short walk during the day or even sitting close to a window if you are unable to get outside.
- **Avoid drinking too much before bedtime.** Drinking lots of fluid close to bedtime will fill your bladder, resulting in frequent awakenings. Don't drink too much in the hour or two before you go to bed and make sure that you go to the bathroom before going to bed.
- **Avoid going to bed hungry or on a full stomach.** This can make it harder to sleep. A light snack can be helpful about 1 hour before bedtime. For example, carbohydrates (e.g., crackers, bread, cereal, fresh fruit) are a good idea. It is also important to allow time for digestion after dinner – try not to go to bed less than 2 hours after dinner.

Set realistic goals

It is important to set realistic sleep goals that match your own sleep needs. For example, although the average sleep time for most adults is 8 hours, different people need different amounts of sleep. That means you may only need 6 or 7 hours to function well during the day.

Try recording your sleep in a diary to keep track of how much sleep you get for a few weeks. You could use the **My Hormone Therapy Diary** in the HT&Me website for this. If you find that you are only sleeping for 6.5 hours for example, despite trying out the hints and tips above, it may be that you only need 6.5 hours. In that case, setting a goal of 8 hours will not benefit you, but only make you feel worse when you do not achieve this.

Healthy living to improve sleep

In addition to helping you to feel generally better in yourself, the following suggestions have been shown to help with poor sleep.

Keep active

Being active and taking regular exercise helps you to fall asleep easier and get deeper sleep at night. Walking, aerobic exercise and resistance exercise can all have sleep-enhancing effects.

You can find more information, advice and tips in the Being Active section of the HT&Me website, which you can find under Healthy Living, Healthy Mind.

Try to limit your caffeine consumption

Caffeine can cause difficulty in falling asleep, awakening during the night and shallow sleep. This is especially true if you consume large amounts of caffeine (e.g., coffee, tea, cola, or chocolate) after 6pm and, especially, close to bedtime. You may find it helps to limit your caffeine consumption to just the morning.

Try to limit nicotine, particularly at night

Like caffeine, **nicotine is a stimulant, which means it makes you feel more awake.** We know that smokers experience significantly worse sleep than non-smokers. You may consider not smoking close to bedtime or in the middle of the night.

Try to avoid excessive alcohol before bed

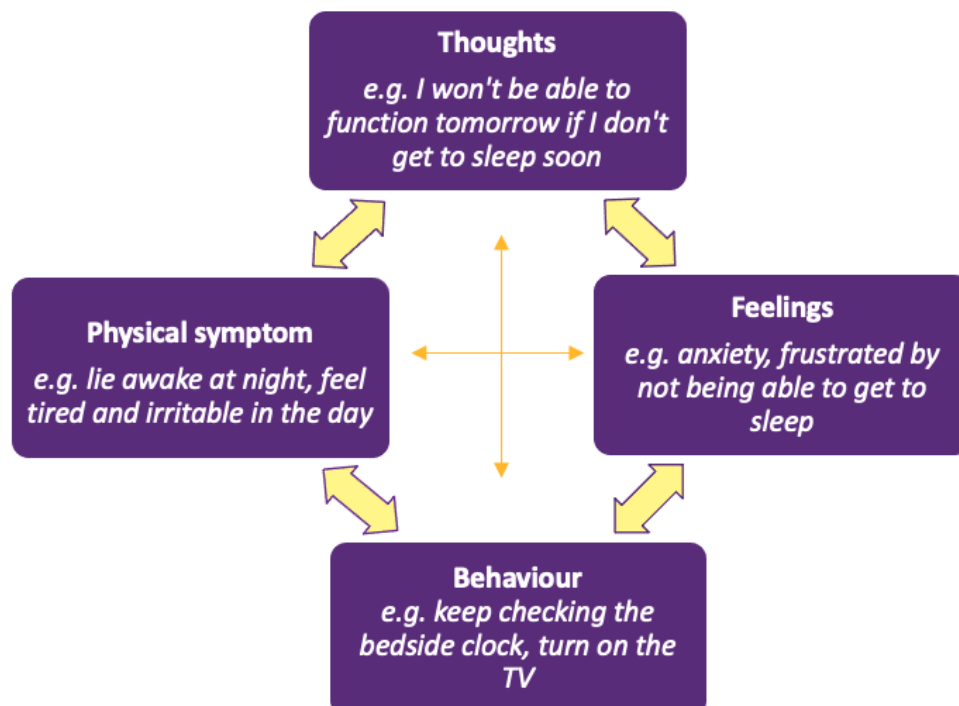
For some people, a small amount of alcohol before bedtime can help them to wind down, feel less stressed and more relaxed, and they fall asleep more easily. However, excessive alcohol consumption in the evening often leads to fragmented sleep and early morning awakenings. Drinking alcohol can also increase hot flushes and night sweats which can affect your sleep.

Changing the way you think and feel about sleep problems

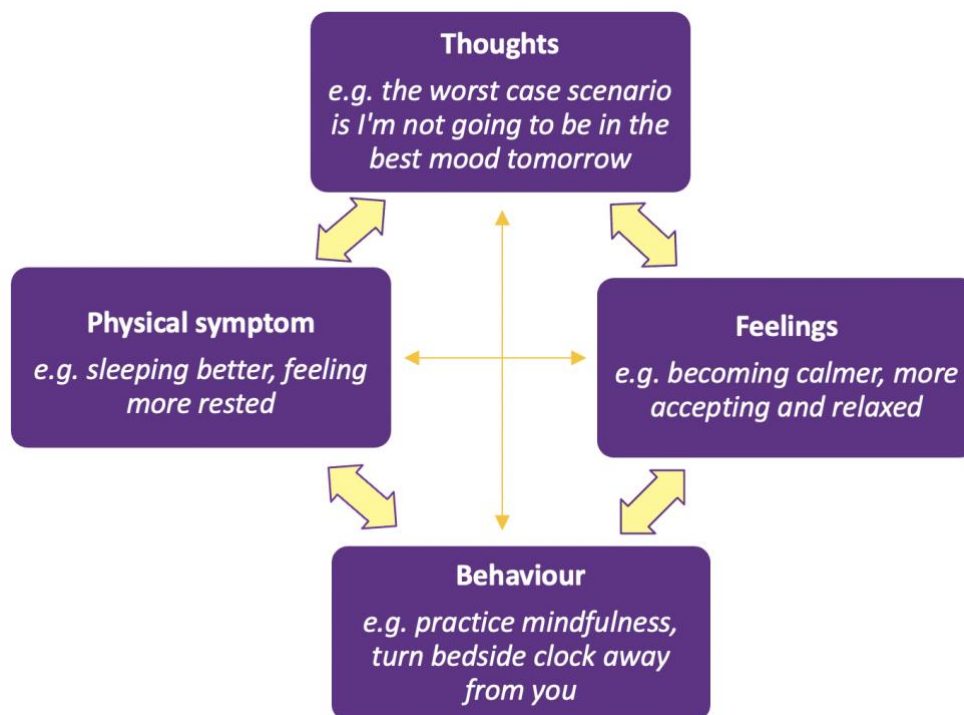
Problems with sleep can be stressful and being anxious and stressed can make it more difficult for you to fall or stay asleep. So, **combatting stress could help to improve your sleep.**

Cognitive (thinking) behaviour therapy (CBT) focuses on the links between physical symptoms, thoughts, feelings, and behaviour. Cognitive and behavioural strategies, or tips, can be used to develop a calmer or more accepting view of a situation and help you to feel more in control.

For example, when you are having problems sleeping, you may be worried that you won't be able to function the following day if you don't get to sleep soon. This will likely lead to feelings of anxiety or frustration at not being able to get to sleep. You may feel the need to keep checking the clock by the bed or find yourself turning on the TV in the hope that it will make you feel more tired. These behaviours can actually make it harder for you to fall asleep and make you feel worse the next day.



CBT can help you to find ways to reduce these negative reactions to difficulties sleeping. **Learning calmer more neutral responses may help you to feel more in control and more able to cope.** This, in turn, might help to improve your sleep. For example, instead of worrying that you won't be able to function the next day if you don't get to sleep soon, a more supporting thought could be that realistically, the worst-case scenario is that you may not be in the best mood the next day. This should help take pressure off you and lead to you feeling calmer, more accepting, and more relaxed. You may feel able to practice mindfulness. This should lead to you sleeping better, and generally feeling more rested.



Change the way you think about sleep problems

Often women's main types of worries about problems with sleep tend to be focussed around:

- The impact of sleep problems – *"I won't be able to function tomorrow"*
- Lack of control – *"I will never learn how to sleep better", "I can't cope with this"*

You might find it helpful to spend some time thinking about your own concerns and worries around your sleep problems. Becoming aware of these thoughts will help you to reduce any negative feelings or behaviours that accompany these thoughts. This should hopefully make you feel more relaxed at night, and more able to sleep.

Notice what goes through your mind when you cannot sleep. You may want to think about situations where you find yourself particularly stressed by your sleep problems. You can use this box to note down what types of thoughts about sleep go through your head whilst you are trying to sleep.

Once you have identified your thoughts when experiencing sleep difficulties, try to develop some calmer, more self-supporting responses. For example:

Self-critical response	Self-supporting response
I won't be able to function tomorrow	Although it might make me not feel in the best mood, sleep loss will not necessarily have a big impact on my ability to function
I can't cope with this	I've coped before on not much sleep and I can cope with this now
I'm never getting any sleep	I am probably getting more sleep than I think

It might help to ask yourself:

- Is this thought really accurate?
- What would a close friend/family member say to me?
- What would I say to them if they were also having sleep difficulties?
- What would a self-supportive alternative be?

My thoughts activity

You can use the box below to note some of your thoughts which may be more negative or critical. Once you have listed these, write and develop an alternative and more supportive thought for each one: use the questions and suggestions above to help you.

Critical, negative thoughts	Supportive, neutral thoughts
	➡
	➡
	➡

Use a diary to track your sleep

You may find it helpful to try recording your sleep patterns in a diary. Try making a note of any physical symptoms that might be keeping you up at night, whether any changes you make to your sleep routine or sleep environment are helpful or whether you sleep better or worse after certain foods or drinks.

You can use the My Hormone Therapy Diary on the HT&Me website for this if you wish.

Keeping a record can be helpful and can remind you of what works for you, and what doesn't. If you need to ask your GP for help, it may also be helpful to share the diary with your GP.

Ask your breast cancer team or GP for help

We hope that the hints and tips in this section give you some effective sleep strategies, and helps you to feel more in control of your sleep – leading to better sleep.

However, **if your sleep problems become very difficult for you or get worse as time goes on, and badly impact on your day-to-day life, it is important to talk to your breast cancer team or GP.** They may be able to suggest something which will help.

Treating sleep problems with sleeping tablets

If sleep becomes very difficult and is affecting your daily life, it can sometimes help to take a short course of sleeping tablets (e.g., 1-2 weeks). These would usually be prescribed by a GP. If you think this may help, talk about it with GP. They can advise whether tablets may be suitable for you and your situation. Remember, as with all medicines, sleeping tablets can cause side effects.

Treating sleep problems with over-the-counter remedies

Over-the-counter sleeping tablets or herbal remedies (such as valerian) can be useful for treating sleep problems in the short term. However, many people find they develop a tolerance to these remedies if they take them for long periods. You could discuss your options with a pharmacist

Further help and support

What should I do if these problems are really impacting on my life?

If these hints and tips do not help and problems with sleep become very difficult for you, or get worse as time goes on, and badly impact on your day-to-day life, it is important to talk to your breast cancer team or GP. They may be able to suggest something which will help.

Support from Breast Cancer Now Nurses

You may find it helpful to use the confidential 'Ask our nurses' email service on the Breast Cancer Now website, especially if you find it difficult to talk to someone in person. To access this, type this weblink into your browser:
<https://breastcancernow.org/information-support/support-you/email-our-nurses>

Where can I speak to other women?

You do not have to cope with problems with sleep on your own. You may find it helpful to join online forums and support groups to talk to other women who are in a similar situation to you. One example of this is the Breast Cancer Now online forum.

To take a look, type this weblink into your browser:

<https://forum.breastcancernow.org/>

Other websites and resources

Here are links to websites and reading that you may find helpful. To take a look, type the following weblinks into your browser:

- To go to Breast Cancer Now: The research and care charity:
<https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/side-effects/sleep-disruption>
- To go to Macmillan Cancer Support: <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/trouble-sleeping>
- To go to the American Cancer Society:
<https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/sleep-problems.html>
- To go to Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/insomnia/symptoms-causes/syc-20355167>
- To go to The Sleep Council: <https://sleepcouncil.org.uk/>
- To go to Sleep Education: <https://sleepeducation.org/>
- To go to Sleep Foundation: <https://www.sleepfoundation.org/insomnia>

If you feel that you have tried everything and the side-effects are still unbearable, do talk to your breast cancer team or GP who will be able to help you decide what to do. Often, they will be able to switch you to another form of hormone therapy or prescribe an additional treatment to help you. If that still doesn't work, the best decision for you might be to stop taking hormone therapy. Ultimately it is a personal decision taking into account the risks and benefits and what is right for you.

Acknowledgements

The section 'Hints and tips to help sleep' was written by, and edited with permission of Dr Greg Kotronoulas, Lecturer in Nursing & Health Care within the School of Medicine, Dentistry and Nursing, University of Glasgow.