



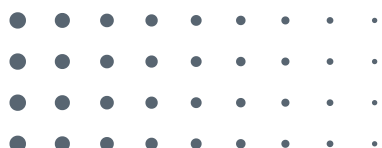
NEUROENDOCRINE CANCER GUIDE

# SLEEP

2023



[www.neuroendocrinecancer.org.uk](http://www.neuroendocrinecancer.org.uk)



If you are having trouble sleeping, there are things you can do that may help improve your sleep.

In this guide we will explore different methods to manage sleep issues. Neuroendocrine Cancer patient and former Ambassador, Sally share her tips to a good night's sleep.



Sleep is involved with many physiologic systems such as memory consolidation, control of inflammation, hormone regulation, cardiovascular regulation and many other important functions.

Sleep problems are often viewed as a secondary symptom rather than a specific problem in its own right, and terms such as sleep disturbance, insomnia, trouble sleeping, impaired sleep and sleep-wake disturbance are often used interchangeably – but there are distinctions.

Research has found that cancer patients show less distinction between daytime and night-time activity – and greater disruptions, in our circadian rhythm, are associated with impaired daytime functioning, severe fatigue and depressive symptoms.

Circadian rhythms are roughly 24hr cycles of physiological, mental and behavioural changes that are maintained by internal biological clocks and are kept in sync with the environment by external cues such as light. Circadian rhythms influence body temperature, hormone release, metabolism, sleep-wake cycles and other important bodily functions. When these rhythms are disrupted, they have been associated with physical and mental health disorders.

Lowery-Allison and Eldridge-Smith (chapter 37) in *Psycho-oncology* (editors Breitbart et al) 4th ed. Oxford University Press 2021





Cancer-related fatigue impacts on, or can be a result of, sleep disturbances and affects many people, before, during and after treatment.

It can have a seriously debilitating impact on lives, but effective interventions have so far proved hard to find. An article in Cancer World '[When more sleep won't do it: tackling cancer-related fatigue](#)' by Sophie Fessl, Sophie explores what might be causing the condition, the importance of distinguishing cancer-related fatigue from the problem of sleep disruption and asks healthcare providers and patients, including a former patient Ambassador, Sally Jenkins, about how they manage it:



Sally Jenkins

Neuroendocrine Cancer patient

Fatigue rules my life. Having a long-term condition that will never be cured leaves us NET [neuroendocrine tumours] patients not only with the physical effects from therapy and the tumour burden, but also with a psychological fatigue. Psychological support is necessary to be able to accept the situation and maximise quality of life – to enjoy the good things and not regret what had to be given up.

I know now how to manage my physical and psychological fatigue. I've found yoga extremely useful as it allows me to work within my limits. And my yoga teacher is very understanding when I fall asleep in class – they put a blanket over me, I snooze for ten minutes, and then continue with the exercises. I couldn't do that in an aerobics class! Personally, I recommend recognising your own limits, then accepting and working within them. This approach allows me to maintain a reasonable quality of life, but it is not the same quality of life as before the diagnosis.





## So what can help?

As Sally has mentioned, in the above article, learning to understand and manage it can help:

- Recognising and understanding the possible causes and acknowledging the impact it is having on you can help in being able to discuss the issue with your healthcare team. So that they can understand the effect it is having on your well-being and provide support, intervention (as required) and information
- Age – this can impact on pattern of sleep and how much sleep we may need
- Fatigue – physical and / or psychological fatigue
- Other symptoms that may be affecting your sleep – such as pain, itching, breathlessness, etc.
- Preferences – where you sleep, the temperature of room, lighting, bedlinen, your usual routine – “early bird” or ‘night owl’, etc.
- Experiences and the outcome of previous strategies / treatment(s) – what has helped in the past
- Having information about the range of interventions and strategies available to you – such as psychological support and self-care techniques.

Fabi et al (2020) Cancer-related fatigue: ESMO Clinical Practice Guidelines for diagnosis and treatment. *Annals of Oncology* (article here) – on assessment.

## Self-care & Healthcare

Good symptom control – effective management of the symptoms associated with Neuroendocrine Cancer as well as potential effects and/or consequences of treatment.

**Healthy eating** – for most people a well-balanced diet is sufficient – but you may need to include dietary supplements or make dietary adjustments dependent on your personal requirements. You can ask your specialist team about dietician support. Our diet & nutrition page is [here](#).

Exercising regularly, as little as 20 minutes, three times a week, can promote better sleep, although this may be best done when there is time to relax and/or cool down afterwards – so not too close to bedtime! – and exercise does not necessarily mean going for a run – it could be any physical activity that you may be able to do – such as a short walk around the block, gardening, tai chi, etc.



## Stimulus Control Therapy

Also known as developing a pre-bedtime ritual. This may involve:

- Reading, listening to relaxing music, drinking herbal tea (such as chamomile or lavender), a warm bath or just having some quiet time.
- Going to bed only when sleepy, and when unable to fall asleep (or go back to sleep) after 20 minutes, leave the bedroom and return when sleepy.
- Maintain a regular wakeup time.
- If you need to rest during the day – try to limit your nap to 30-45 minutes.
- Use the bed for sleep and sexual activities only.
- Try to avoid watching television, eating, or reading on a phone/tablet/or similar device in bed. – listening to relaxing music, an audio book or relaxation App however may help.

When done regularly, this routine will signal to your brain that it is time to go to sleep.

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## Relaxation Therapy

Includes muscle relaxation, biofeedback, imagery training, hypnosis, and mindfulness: deep breathing, stretching and / or meditation exercises can be relaxing. There are self-help guides and Apps that can help you to learn these techniques – and /or you can discuss with your team who may be able to refer or signpost you to professionals who specialise in instructing these techniques. For example, [Neuroendocrine Cancer UK's counselling service](#) and / or local cancer centres, such as Maggie's Centres.

A warm bath, warm glass of milk or cup of chamomile tea at bedtime can help to induce a restful state.

Try to avoid alcohol, as although it may cause initial tiredness, it can lead to fragmented sleep.





## Psychological Support

Can help in dealing with psychosocial issues that may be interfering with sleep. For example, anxiety, or in developing new ways of thinking about sleep difficulties or fatigue, which can sometimes be quite negative and unhelpful. Changing viewpoints can help to recognise and set boundaries, encouraging a more positive acceptance of personal needs and limitations:

*“Fatigue taught me to listen to my body”.*

Finding a new or adapted pace of life. Some people find it helps to focus on stopping doing an activity: having a break, sitting or lying down to rest or sleep, resting and waiting for it to pass and/or avoiding physically straining activities.

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Others re-shape their daily lives: living their life day by day, planning, prioritising, reorganising life and work and balancing activities. Or as we sometimes call it the four Ds:

1. Do
2. Delegate
3. Defer or
4. Dump!

*“If I’m more tired, it’s not the end of the world, so I’ll rest and do less. It’s not the end of the world and it’s possible to live well, if at a slower pace than I was used to doing”*

This last point is an echo of something many of you may be familiar with – and that is Spoon theory – which is a way of describing the amount of mental or physical energy a person has available for daily activities and tasks – and how this can be used to help you manage your own energy levels and well-being.























## The Spoon Theory

# The Spoon Theory



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

**If you only had 12 spoons per day, how would you use them?** Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

			
			
get out of bed	bathe	make & eat a meal	go to work/school
			
get dressed	style hair	make plans & socialize	go shopping
			
take pills	surf the internet	light housework	go to the doctor
			
watch TV	read/study	drive somewhere	exercise

The Spoon Theory was written by Christine Miserando, which you can check out on her website [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com).

By Christine Miserando – [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com)





## Apps and Resources that may be useful:

NHS resources:

<https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>

<https://www.nhs.uk/oneyou/every-mind-matters/>

Counselling:

<https://www.neuroendocrinecancer.org.uk/supporting-you/counselling/>

**Headspace** – Daily mindfulness techniques.

**Buddhify** – Short mindfulness exercises for help with pain, insomnia, worry etc.

**SAM** – Self-help techniques for anxiety, panic and worry – nb white cloud, blue background.

**UNTire** – Techniques for managing energy.

**Pzizz** – aims to help you calm your mind, fall asleep fast, stay asleep, and wake up refreshed.

**Sleepio** – is a 6 week online program designed by sleep experts and based on cognitive and behavioural techniques

