

# Sleep Management and Lymphoma



## OVERVIEW

Sleep problems are very common for people with lymphoma and chronic lymphocytic leukaemia (CLL). Difficulty sleeping can commence immediately after diagnosis and may continue for many years following completion of treatment. Unhelpful sleeping patterns and insomnia can have significant negative effects on day to day functioning, and over time can drastically impact your quality of life.

Sleeping problems can include difficulty falling asleep, staying asleep, waking early and acute and chronic insomnia (three or more months of disrupted sleep). Breaking the cycle can be very difficult, although it is possible and made easier by following some of the tips and strategies outlined in the following fact sheet.

## WHY CAN'T I SLEEP?

For someone with lymphoma or CLL, there are usually multiple causes of disrupted sleep, and these can be different for each person. If you are receiving chemotherapy, you will likely be taking high doses of steroids with your other medications. We know that steroids can have significant impact on your ability to sleep. Generally speaking, the benefits of the steroids generally outweigh the negative side effects. It is helpful to know that many people feel that the effects of steroids wear off after 24 hours or so, enabling better sleep in the days after treatment.

Other causes of disrupted sleep can include:

- Anxiety, stress and worry
- Fears about the future
- Hot sweats & flushes at night
- Pain
- Day time napping due to high levels of daytime fatigue
- Change in routine
- Obstructive sleep apnoea

## HOW DO I BREAK THE CYCLE OF DISRUPTED SLEEP?

In order to start addressing your sleep concerns, it can be helpful to begin a 'sleep journal' which you can use to document your sleep and wake times each night. This can help

identify patterns and will also be useful if you choose to see a psychologist or other health practitioner for sleep-related concerns. The following strategies may be helpful in managing your sleep-cycle. It is recommended that you allow four to six weeks of implementing changes before assessing any improvements to your sleep:

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|---|---|
| <b>Change your bedtime routine</b>      | Slowly unwind from the day with a calming routine that may include a warm shower or bath, meditation or listening to relaxing music.  |
| <b>Challenge your thought processes</b> | Address any previously held beliefs about sleep and assess whether they are accurate or even helpful. For example, "If I don't get 8 hours of sleep tonight, I won't be able to function" or "I need to sleep in tomorrow so that I can catch up on missed sleep". It can be helpful to challenge these beliefs and replace with more helpful and relaxed thoughts. For example, "I will be able to manage tomorrow if I only get 3 or 4 hours of sleep tonight". |
| <b>Make bed a place only for sleep</b>  | Non-sleep activities such as reading, watching TV, browsing on your phone and listening to music should be done somewhere else in the house. This teaches your mind that your bed is a place only for sleep.  |
| <b>Distract yourself</b>                | If you don't fall asleep within 20-30 minutes of going to bed, leave the room and do something else distracting and calming. Remaining in bed after this time may just make you more frustrated. Leave the room and read a book, have a warm drink or flick through a magazine until you are sleepy again then return to bed and try the process again.   |
| <b>Don't check the clock</b>            | If you wake during the night, it may be tempting to check the time on your clock or phone. This will only make you more awake and generally more anxious or frustrated.   |

# FACT SHEET

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| <b>Don't spend too much time in bed</b>          | Try to restrict the amount of time spent in bed to set hours, but only go to bed if you are sleepy. If you are very unwell, this strategy may not be suitable for you.  |
| <b>Create an environment conducive for sleep</b> | Darken the room, use light-blocking curtains or eye masks if needed. Use ear plugs to block out extra noise. Ensure your bed sheets and pyjamas are comfortable. Adjust the temperature in the room if you are able (18 to 22 degrees is optimal) |
| <b>Create a bedtime and wake time</b>            | Set an approximate bedtime, but only go to bed at this time if you're sleepy. Having a regular wake up time each morning is much more important.  |
| <b>Avoid napping</b>                             | If you really feel you need to nap due to significant fatigue, try and aim for 30 minutes or less and only before 3pm.  |
| <b>Practice self-care</b>                        | Look after your body and mind with regular exercise, a healthy diet, drinking water but limit water consumption after 6pm, mindfulness, meditation, limiting alcohol and nicotine.  |

## BUT WHAT IF I'M TOO WORRIED TO SLEEP?

Some additional strategies may be helpful when you are struggling with high levels of stress and anxiety:

- Talking about your concerns, fears and worries with a family member or close friend
- Talking to a counsellor, psychologist or spiritual care worker to address your emotional concerns
- 'Worry time'. Setting aside time during the day (a half hour to an hour) which is allocated purely for worrying. You can worry as much as you like during this time, the idea being that when you go to bed you have already done your worrying for the day.
- Medicinal options. Talk with your GP about medications which may help you manage your stress levels and sleeping concerns
- Keep a journal of your experience each day including your thoughts, feelings and emotions. Some people find it helpful to write in their journal prior to going to bed, as a way of unloading their thoughts.

It is important to note that what works for some people may not work for others. The strategies listed in this fact sheet may not be effective for you, but it is helpful to know that there are many

other resources and support options available. Don't hesitate to call the lymphoma nurse support line on 1800 953 081, or email [nurse@lymphoma.org.au](mailto:nurse@lymphoma.org.au) if you would like more options or advice.

## RESOURCES AND SUPPORT

| Organisation                                       | How can they help?  |
|--|---|
| Lymphoma Australia                                 | <ul style="list-style-type: none"> <li>• Lymphoma Australia offers a wide variety of resources and support for people with lymphoma or CLL and their carers. Please visit our website <a href="http://www.lymphoma.org.au">www.lymphoma.org.au</a> for further information</li> <li>• Lymphoma Nurse Support Line: 1800 953 081 or email: <a href="mailto:nurse@lymphoma.org.au">nurse@lymphoma.org.au</a></li> <li>• Online private Facebook group: Lymphoma Down Under <a href="http://bit.ly/2mrPA1k">http://bit.ly/2mrPA1k</a></li> <li>• For more information, watch the 'Getting a Better Night's Sleep: Understanding and Managing Sleep Problems in Cancer' video presentation featuring psychologist Justine Diggins, Peter Mac. View at: <a href="http://bit.ly/32ksdGZ">http://bit.ly/32ksdGZ</a></li> </ul> |
| Calm   | <ul style="list-style-type: none"> <li>• Calm is a free smartphone app which contains over 100 guided meditations for anxiety, stress and sleep management. From beginners to advanced listeners. Visit: <a href="http://www.calm.com">www.calm.com</a></li> </ul>  |
| Can-Sleep Program at Peter MacCallum Cancer Centre | <ul style="list-style-type: none"> <li>• Can-Sleep: Making night-time sleep problems go away – a guide for people with cancer: <a href="http://bit.ly/31aYjDA">http://bit.ly/31aYjDA</a></li> </ul>   |
| Sleep Health Foundation                            | <ul style="list-style-type: none"> <li>• Australian charity dedicated to creating awareness about sleep problems &amp; providing education on sleeping issues and solutions. Many relevant resources on different sleep problems/disorders and strategies, visit: <a href="http://bit.ly/2VBgAIU">http://bit.ly/2VBgAIU</a></li> </ul>  |

This resource was last reviewed and updated October 2019