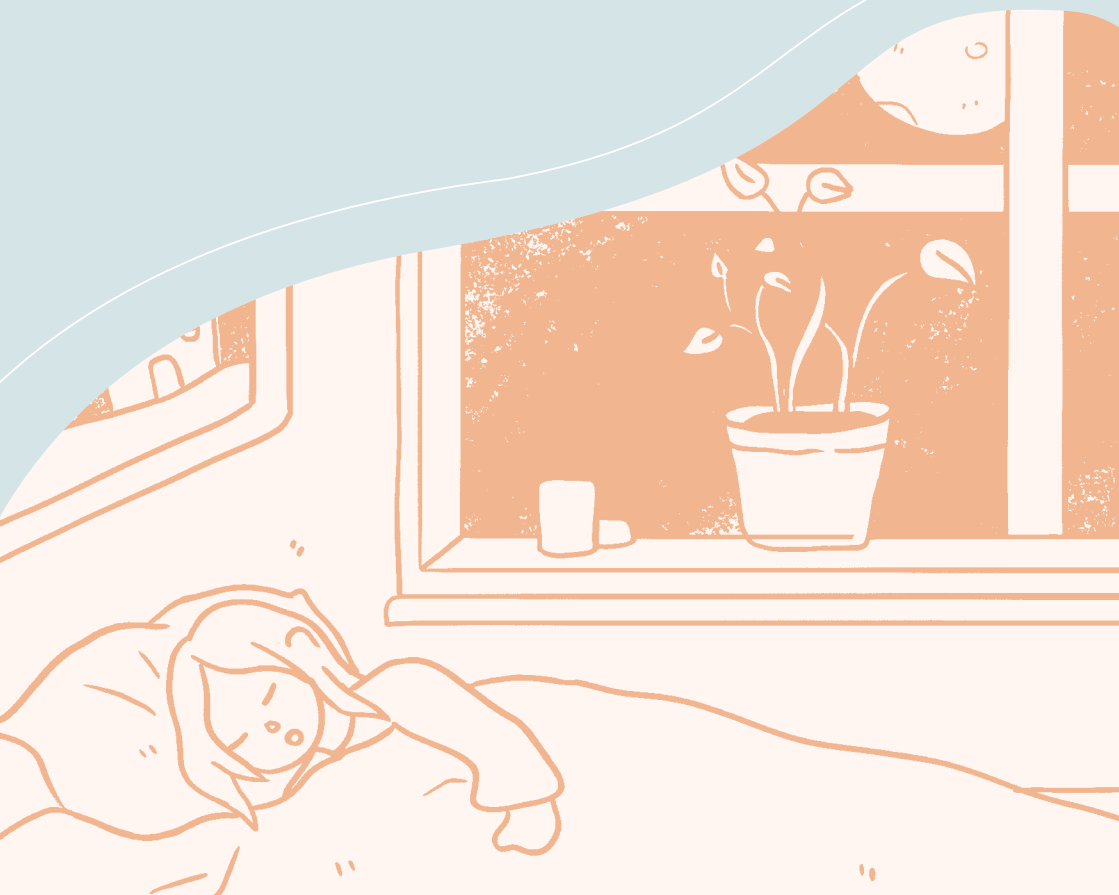


CAN-SLEEP

A Guide to Sleep for Young
People who have had Cancer



“

Learn to love your sleep. It is going to help you heal, it is going to reenergise you. Sometimes we avoid sleep because we don't want to miss out. But if you are fatigued, you are going to miss out more because you are not going to be present.

– Jess, 23 years

”



Foreword

As young people, many of us experience sleep difficulties following our cancer diagnosis. Cancer is stressful, and when stressful thoughts kick in, they can make getting to sleep (and staying asleep) extremely difficult.

There are many other factors though, aside from stress, that impact our sleep. Cancer can change our body and how we feel. Side effects of medication in conjunction with other treatment can make sleep challenging. Early ward rounds, overnight observations with the beeping of medical equipment and just being in hospital make it really hard to get some rest at a time when we actually need it the most. But even when treatment ends, many of us find that sleep may still be a problem.

That's why we are delighted to be involved in the development of this resource which specifically helps

young people with cancer who are experiencing sleep difficulties. *Can-Sleep: A Guide to Sleep for Young People* who have had Cancer has been developed by experts who work with young people, in cancer care and sleep medicine.

We hope that this resource provides you with information you need to improve the sleep problems you may be experiencing, and encourages you to talk to your healthcare team if you need further assistance.

Victorian & Tasmanian Youth Cancer Action Board



Top Tips and Tricks for Good Sleep

This resource provides heaps of strategies to help you to improve sleep. Our top tips are:

- Be kind to yourself and take your time to recover
- Identify sleep problems early
- Develop healthy thoughts about sleep
- Keep bed a place for sleep
- Having a routine is key
- Look after your mind and body
- Track your sleep
- Ask for help when you need it.

About this resource

Sleep is crucial for our health, mental health and wellbeing. But young people tell us that cancer can impact sleep in many ways.

This self-management resource aims to help you to understand common impacts on sleep and strategies that can optimise your sleep.

Based on a project called **Can-Sleep**, that addressed sleep difficulties for adult cancer survivors, this resource was developed for young people through collaboration between:

- Peter MacCallum Cancer Centre
Department of Psychology

- ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service
- The Victorian and Tasmanian Youth Cancer Action Board.

The content is based on focus groups with young people who have had cancer between the ages of 15-25 years. Each section covers a different topic. You can read the entire resource or just the section that is most relevant to you now.

Introduction

Is this resource for you? What can help with sleep?
How long before sleep gets better? Other help.

All You Need to Know About Sleep

Why do we sleep? Why it is so important? Sleep as
a young person. General factors that can impact
sleep. Sleep Problems.

Sleep Impacts

The common impacts of cancer on sleep for
young people.

Strategies to Improve Sleep

Strategies that can help with sleep including
general strategies and cancer specific approaches.

Information for Others

Information for parents, carers, partners and
health professionals.

Last Word

Take home messages.

More...

More information including: Our Sleep Tracker,
space for notes, a glossary, useful links &
resources and a bibliography.



How to use this resource

To navigate this resource look out for the icons below. There is a glossary of common terms at the end, a sleep diary and notes pages as well. These can help you to identify unhelpful thoughts and behaviours to do with sleep as well as useful strategies to optimise your sleep.



Good to Know



Tips and Tricks



More information

Introduction

Sleep problems are extremely common in young people with cancer. They can occur from the time of diagnosis and can sometimes last for many years after treatment.

BB *I really recognise the importance of sleep now, after having had cancer... I recognise what happens when sleep is disrupted and how that impacts my ability to function the next day.*

Sleep problems can include short-term sleep disturbance (which may be caused by cancer treatment, side-effects or worry), or longer-term sleep problems such as insomnia. We know that as many as 6 in 10 cancer survivors experience insomnia. Sleep problems are therefore a big challenge, and they often impact on daily life and well-being. The good news is that there are many things that you can do to help you to improve your sleep.

Is this resource for you?

This resource is for you if you are a young person who has had a diagnosis of cancer. It is also for you if you are supporting a young person who has had cancer as a parent, partner, sibling, peer or health professional.

As a young person, everyone's experience is different, and you may experience a lot of impacts on sleep or only a few. Whatever your experience, this resource can help you to:

- Understand common sleep problems
- Improve existing sleep problems
- Cope better if new sleep problems arise
- Prevent sleep problems getting worse.

What is cognitive behavioural therapy (CBT) for sleep?

This resource contains a range of helpful tools and strategies that you can use to gain some control over your sleep. These methods are referred to as Cognitive Behavioural Therapy (CBT). CBT aims to bring about positive changes by examining and adapting our:

- Thoughts and beliefs (cognitions)
- Feelings (emotions)
- Actions (behaviour).

CBT for sleep focuses on how we think about sleep and our sleep behaviours. It offers ways to manage the impact of stress and worry on sleep. While sleep medications can be useful for sleep for short periods of time, they can have side effects. CBT is safer and may lead to longer lasting improvements in sleep. CBT is also the recommended treatment for sleep problems such as insomnia.

How to use this resource

There are usually many factors that can impact sleep. For this reason, it is often best to use a range of different approaches to improve sleep. This resource outlines lots of ideas and strategies you can try. It is a good idea to pick the approaches that seems the most relevant and do-able for you!

There are spaces throughout the resource to identify unhelpful and helpful thoughts, feelings and behaviours as well as write down the strategies that may work best for you.

Professional support

Some people may find it most beneficial to work on sleep problems with the help of a health professional. At the end of this resource there is a section for health professionals to help them to work with you to address sleep concerns. Involving a health professional may be particularly important if your sleep is impacted by:

- Ill health
- Distress or mental health concerns including anxiety or depression
- Medication side effects
- The effects of drugs or alcohol

Sleep problems can also sometimes be:

- Related to too much sleep (such as excessive daytime sleepiness)
- Cancer related fatigue (if there are no night-time sleep problems)
- Medical sleep disorders such as sleep apnoea, or restless leg syndrome.

These conditions need different treatment to the strategies included in this resource. If you think any of these are relevant to you, you should discuss this with your medical team or general practitioner (GP) and ask for help and support.

All you need to know about Sleep...



Sleep really affects my mood... if I don't get enough sleep, I'm not myself, I'm not present and struggle to concentrate... sleep is very very important to me.

Sleep is really important for our health, daily functioning and our wellbeing. This section explains why sleep is important. It also explains why our sleep as a young person is different to our sleep as a child or older adult. This section also talks about the general factors that can impact sleep (impacts that result from cancer and treatment are explained in the next section) and common sleep problems. This will help you to understand any sleep problems you are having so you can make a plan to manage these and improve your sleep.

Why is sleep important?

We all need to sleep. Sleep helps us regain our energy and repair our bodies. Sleep also helps our brain to process information, store memories and learn. Without enough sleep we don't function at our best. There are different stages of sleep that we cycle through during the night. Some stages of sleep include:

- **Deep sleep**

This is the most important sleep for restoring our energy. It occurs in the first three to four hours of sleep.

- **Rapid Eye Movement sleep (REM)**

This is the stage of sleep when dreams occur. Most REM sleep happens in the last three to four hours of sleep.



Waking up during sleep is normal.

Most people wake up, briefly, several times during the night. This is different to sleep disturbance and fatigue.

Sleep as a young person



When you are an adolescent, it is time where you are very sleepy, you want more sleep and you don't feel awake and alert when you get to school at 8:00am.

Sleep as a young person can be challenging because biologically our bodies need different hours of sleep compared to children or older adults. Despite this, we still have to go to school or work early and fit in other activities like socialising with friends and family. We also often have priorities other than sleep.

Everyone's relationship with sleep is different too. Some find it easy to sleep and others find it more difficult. Some young people need more sleep than others, some need less sleep. Often the hours that you want to sleep don't align well with the things we have to do in a day. Many young people also tell us that they don't have a regular sleep routine which can really impact the quality of sleep as well.

BB Before cancer, sleep was kind of like an inconvenience because there were just not enough hours in the day.

BB Before diagnosis I would sleep ok during the week because of school but during the weekends I would game all night, socialise online...

General factors that impact sleep:

There are lots of factors that can impact on sleep normally, outside of cancer and treatment. These include:

- **Sleep drive (or our 'hunger' for sleep)** - Sleep drive increases over the day as you stay awake longer. A high sleep drive at bedtime helps you fall asleep faster and stay asleep longer. Sometimes, napping during the day can reduce your sleep drive and make it hard to fall asleep at night.
- **Body clock (circadian rhythm)** - We all have an internal 'body clock' that signals when it is time to wake, and when it is time to sleep. The body clock is 'set' by various signals in our environment. The most powerful signals are light (this signals that it is time to be awake) and darkness (this signals that it is time to sleep).
- **Our mind** - An active mind makes it difficult to sleep. A quiet mind tells your body you are 'off duty'. It reduces muscle tension and works with your sleep drive and body clock to get a good night's sleep. The emotional stress of having cancer can make it hard to have a quiet mind and make it particularly hard to sleep. Moments of heightened stress may include at initial diagnosis, when waiting for or receiving test results or scans, at times of change and during life transitions.
- **External factors** - These include factors that are in our environment and sometimes out of our control. They can include noise, studying or working irregular hours, screen time and gaming a lot and having carer or parenting responsibilities.
- **Internal factors** - These relate to your body and can include cancer itself, treatments including surgery, chemotherapy and radiotherapy and medications such as steroids, which can keep you awake. There are many treatment side-effects that can impact sleep.



See "Common impacts of cancer on sleep" on page 12.



Identify any general factors that are impacting your sleep at the moment:



See “Looking after your mind and body” on page 29.

This gives information on how to manage stress and quiet your mind.

Sleep problems

There are many different types of sleep problems. The most common are sleep deprivation and insomnia. It is important to know that most sleep problems are temporary and can be managed with the right strategies.



Our body is really good at catching up on sleep

After long periods of sleep loss, one or two nights sleep can restore our body and function to almost normal.

Sleep deprivation

Sleep deprivation occurs when we don't get enough sleep. Brief periods of sleep deprivation are normal. But long periods of sleep deprivation can impact on our health, daily function and wellbeing. This can lead to problems including:

- Poor concentration and memory
- Low energy and fatigue
- Irritability or frustration
- Tearfulness
- Difficulty thinking clearly and making decisions
- Reduced ability to cope with pain, illness, or stress.

Insomnia

Insomnia is different to short term sleep deprivation. When you have insomnia, sleep is difficult even when the conditions for sleep are right. For example, falling asleep or staying asleep is difficult even when you are sleepy, comfortable, or in a quiet environment. Insomnia can occur for short periods of time (days/weeks) or longer periods of time (months/years).

Signs of insomnia include:

- Difficulty falling asleep or falling back to sleep
- Waking up in the middle of the night, or too early
- Feeling unhappy with the amount or quality of your sleep
- Daytime problems, such as fatigue or difficulty concentrating
- Distress or anxiety about not sleeping well.



If you think you have insomnia, it is important to talk to a health professional.

This is because some of the signs are the same as impacts of treatment (like fatigue). It is important to work out whether these are related to insomnia or not, so you can get the best support.



If you are feeling fatigued, don't feel afraid to talk to your doctor about it, to work out why



If you have insomnia, the most important strategies in this resource are...

- “Developing healthy thoughts about sleep” on page 21
- “Keeping bed a place for sleep” on page 23
- “Spending less time in bed” on page 24
- “Looking after your mind and body” on page 29

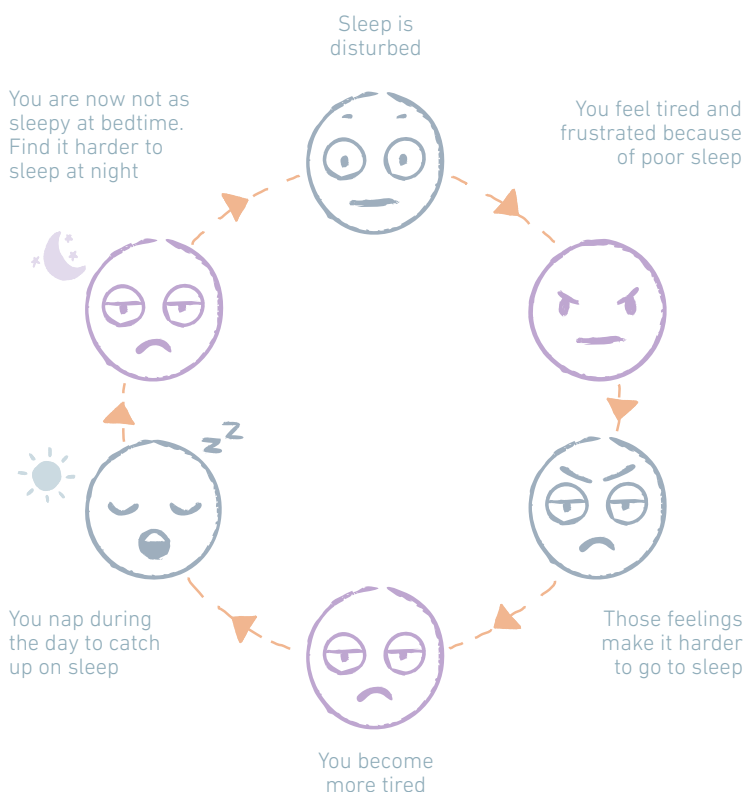
The cycle of sleep problems

The challenge with sleep problems is that the way we respond to them can sometimes make them worse. When our sleep is disturbed, we can feel tired and frustrated. This can make it even harder to sleep which makes us more tired and more frustrated. And the cycle continues. This is why it is important to understand any sleep problems and do something to manage these as soon as you notice them, to improve sleep.



There are strategies that can help to manage sleep problems and improve sleep

That's what this resource is for. But you can also talk to your healthcare team or GP at any time if you are having problems with sleep.



Common impacts of cancer on sleep...

Prior to diagnosis my sleep was quite good but after diagnosis, with the side effects of chemotherapy and radiation, my sleep was disturbed quite a bit...especially with work as well because I am a shift worker so it's really hard to balance everything. When I only have very few hours I feel very uncoordinated and lethargic



Managing normal life stressors and sleep can be tough. But cancer and treatment can also impact sleep in many ways. This section talks about common impacts from young people who have experienced cancer.

Common impacts of cancer and treatment

It is useful to understand that cancer and treatment have lots of impacts on our physical, mental and social

health and wellbeing. These can all affect our sleep either physically, or by creating stress, worry and anxiety. Because everyone’s experience is different, it is important to identify the impact relevant to you so these can be managed.

Common Health Impacts for Young People who have had Cancer		
Common Physical & Cognitive Health Issues*	Common Mental Health Issues	Common Social Health Impacts
Pain, swelling or scarring, tingling or numbness.	Depression or low mood	Changed relationships or problems in relationships with family members
Fatigue (being really physically or mentally tired a lot of the time or needing a lot of rest or sleep)	Anxiety, excessive worry in general, worry about the future and/or worry about cancer returning	Changed relationships or problems in relationships with partners
Changes to mobility, weight, hearing, eyesight and/or hair	Persistent sadness, crying or a sense of grief or loss	Changed relationships with friends
Changes to hormones, hot flushes (for women) and/or night sweats	Anger, irritability, lashing out, frustration or feelings of guilt	Feeling like other people don't understand you or your experience or worries

* Cognitive (brain) health refers to how you think, learn and behaviour.

Common Health Impacts for Young People who have had Cancer

Common Physical & Cognitive Health Issues*	Common Mental Health Issues	Common Social Health Impacts
Changes to sexual function and/or fertility	Emotional fatigue or tiredness	Withdrawing from others or being isolated
Difficulty learning or understanding information	A lack of motivation	Not feeling safe at home or problems at home
Difficulty remembering things or concentrating	Withdrawal from others or social isolation	Mood changes (e.g. low mood, anxiety etc.)
Changes to problem solving or planning skills	Not engaging in normal activities or things you usually enjoy (like school, work or hobbies)	Disruption to or problems with school, study or work
Changes to communication	Changes to eating or weight	Problems with money or financial stress
Changes to social skills	Changed identity, changed sense of self or a loss of confidence	Legal concerns or problems

* Cognitive (brain) health refers to how you think, learn and behaviour.



Identify any general impacts from cancer and treatment that are relevant to you:

Common sleep impacts

Young people tell us that they experience impacts to sleep from diagnosis, throughout the cancer journey and can sometimes last years beyond the completion of treatment.

At diagnosis

Impacts at the time of diagnosis are commonly associated with **physical impacts and tiredness** from cancer itself. However, they can also be associated with **stress and anxiety** about treatment and being in hospital and in relation to what may come next.



Leading up to my diagnosis I was feeling very fatigued and I was like 'why am I so lazy, why am I sleeping so much.'

During treatment

Treatment side effects can have a big impact on sleep. These may include pain from surgery and procedures, or nausea from chemotherapy.

BB *I had to have surgery, so I think that probably the biggest issue for me during cancer treatment was the pain that kept me awake. during the night.*

BB *The treatments all, like gave me different side effects. So, with chemo I had a lot of nausea and pain that disrupted my sleep.*

Radiotherapy can make you really tired or fatigued too, especially towards the end of treatment.

BB *I guess with sleep, the big issue for me was fatigue when I was going through radiation. I was sleeping all the time. At the end I was napping twice a day between classes. I would go home, sleep, then do some more study. But it was really not sustainable.*

Many **steroids** cause wakefulness and disrupt sleep. **Hormone treatments** can also have impacts and can cause hot flushes and night sweats. If these are taken with treatments that cause fatigue or tiredness sleep can be particularly impacted.

BB *One thing that really affected my sleep was when I came off the dexamethasone (steroids)...That would affect my sleep as well.*

BB *I also had really bad hot flushes. They're the worst... Fertility treatment that can come with hot flushes too.*

BB *It's hard because some treatments cause you to be more sleepy and others keep you more awake... and it's like there is this battle internally.*

Stress and anxiety also often continue and can be heightened during treatment.

BB Sometimes I would just be awake at 3:00, 4:00 in the morning because my mind just wouldn't switch off.

The **hospital environment** can also be really disruptive to sleep, with regular observations (obs) overnight and early visits from healthcare teams coming to do their rounds or handover.

BB Unfortunately, there are a lot of external factors you can't control when you are in hospital. You just get comfortable and the machines start beeping... or they come in to do obs and at 7:00am a whole team of 20 people walk into your room.

After treatment

The impacts to sleep can also continue well beyond the end of treatment. These can last longer than you expect as your body recovers.

BB It's hard to adjust, that first year, year and a half.

These impacts can be associated with **ongoing treatment side effects**.

BB The main problem has been hormone treatment. One of the side effects is insomnia.

BB I still get a lot of restlessness in my legs from the antinausea meds.

BB Because I had radiation to my pelvis I have to go to the bathroom all the time. I also have pain and cramps.

As the result of my treatment I am completely hydrocortisone (steroid) dependant. I think for me that's probably been the hardest thing. I take steroids three times a day... If I take it too late, my whole night is restless.

Fatigue is common too, as your body needs a lot of time to rest and recover. It can be hard to know what is normal as the result of treatment and what needs to be managed with support. This is why it is really important to talk to your healthcare team if you have any concerns.

You definitely still experience fatigue after cancer treatment. It's a huge thing adjusting from sleeping a lot to easing back into normal' life. Going back to work, life didn't' allow for a nap anymore. It's just trying to get used to that and what to do now? How to manage energy levels? That's really challenging.

I found post treatment it was hard to work out 'am I feeling tired because of post cancer fatigue, am I feeling tired because I'm just tired and I've done a lot or am I feeling tired because there is some side effect that hasn't yet been diagnosed or addressed.

It is also important to recognise that both prolonged sleep disruption and fatigue can impact a lot on the rest of life including school, work and socialising with friends.

Adjusting after and going back to school I had a lot of fatigue and chemo brain, I would just fall asleep in class.

Worry or anxiety can also continue after treatment. Worry may be particularly high before scans or medical appointments. Lots of young people and families report real challenges with sleep around this time.

BB The day before I have a scan, it gives me anxiety and really affects my sleep, because I will just lie there thinking about what's going to happen... I think it's a very common thing to experience. I think a lot of people struggle with that.

Sometimes the experience of cancer and treatment can also mean that we associate **negative feelings** with being in bed or going to sleep.

BB Associating your bed with negative thoughts is still a big problem for me because I associate it with the times of being in bed because of the treatment.

Young people also report feeling **guilty or lazy** after treatment completion as they compare themselves to their friends who haven't had cancer or notice that they can't do as much as they would like to in terms of school, study, work and socialising.

BB I think that's something that you battle with, feeling guilty as a young person that you are sleeping, and you shouldn't be sleeping but in actual fact you are not just napping for no reason, you are very tired.

BB You feel guilty, like why can't I be like my friends, why am I so lazy.



There are strategies that can help to manage sleep problems and improve sleep

While all these impacts are real, and common, the important thing to know is that there are strategies that can help to manage them and improve your sleep and wellbeing. That's what this resource is for. But you can also talk to your healthcare team or GP at any time if you are having problems with your sleep.

Strategies

to improve sleep...



Now for the good news! There are LOTS of strategies that can improve sleep, no matter what your experience. This section covers useful strategies you can try to manage your sleep.

These methods are based on Cognitive Behavioural Therapy (CBT). CBT aims to bring about positive changes to life by examining and changing our:

- Thoughts and beliefs (cognitions)
- Feelings (emotions)
- Actions (behaviour)

CBT for sleep therefore focuses on how we think about sleep, feel about sleep and our sleep behaviours. It also offers ways to manage the impact of stress and worry on sleep.

It is important to remember that everyone's experience is different so it is recommended that you try the strategies discussed here that feel right and do-able for you. It can also take some time before you notice improvements in your sleep, so don't give up.

Developing healthy thoughts about sleep

Our thoughts determine how we feel. Negative thoughts about sleep can make us worry and make it harder to sleep. It is therefore important to recognise (and bust) some common myths about sleep.

It is also important to recognise any unhelpful thoughts we have about sleep. For example, thinking "if I don't sleep, I won't be able to concentrate", "tomorrow will be a write off" or "it is bad for my health". Instead...

- Try reminding yourself that your body is designed to cope with, and adjust to, sleep loss. If your sleep is shorter (fewer hours), then you just move into the deep stages of sleep more quickly. These are the important stages of sleep.
- Instead, try telling yourself "worrying isn't going to help, I need to trust my body to get the sleep I need" to manage your thoughts.



How we think about sleep can determine how well we sleep.

Our thoughts about sleep are therefore really important.

Myth

'I need 8 hours of sleep to function'.

Fact

Everyone's sleep need is different. Sleep can vary across the days. The amount of sleep we need also changes across our life, as we tend to sleep less as we get older. Our bodies can adjust to different amounts of sleep.

Myth

'If I don't sleep well, I should catch up by sleeping in, or going to bed earlier'.

Fact

Our bodies catch up on lost sleep by sleeping deeper and better the next time we sleep. Going to bed early or sleeping late can make it harder for you to sleep when it is best for your body clock.

- Tell yourself: 'If I didn't sleep well last night, I will go to bed when sleepy (and not too early) and get up at my usual time'.

Myth

'I cannot function after a poor night's sleep'.

Fact

You might not feel 100% after a poor night's sleep, but you can probably do most things reasonably well.

- Tell yourself: 'I don't have to be 100% all of the time. 70% is plenty'.
- Avoid thinking that a poor night's sleep will ruin your day, or cancelling plans because you didn't get enough sleep.



Identify any unhelpful thoughts you have about sleep here:



How can you change these thoughts? What are some more helpful thoughts you can have about sleep?

Your bed, bedtime and bedroom

Keep bed a place for sleep (mainly)

Make bed a separate place from where you do other stuff

If you haven't slept well for a while, you may spend a lot of time in bed awake. If this happens, the body learns to be awake when in bed, not asleep.

It can help to make sure you keep bed a place for sleep and not other activities. This reduces frustration and stress. It also re-trains your mind to link your bed with being asleep and helps you feel relaxed, so you can sleep more easily.

To make sure you keep bed a place for sleep and reduce the stress of being in bed while awake, the following steps can help. They may feel awkward or unhelpful at first, but they are very effective, so give them a go.



Bed is also a place for intimacy and that's ok

It is ok to cuddle, kiss and have sex in bed, but try and take all other activities outside (like reading, watching TV, gaming and being on your phone) so that bed is mainly for sleep.

Get up if you can't sleep

The main trick, if you can, is to get out of bed and leave the bedroom if you can't sleep. If after 20-30 minutes of trying to fall asleep you are still feeling awake, stop trying to sleep because this can make you feel frustrated and make it even harder to sleep. Instead, after about 20-30 minutes (avoid looking at the clock, just guess) get out of bed and try to stay calm and relaxed. It can help to...

- Go into another room and do something quiet and relaxing
- Remember that every minute that you are awake, your body gets sleepier
- When you next feel sleepy, go back to bed and try again

You might need to do this many times a night, and that is okay. You may feel more tired when first try this, but it can be really helpful over time so don't give up.



You can't do this if you are in hospital, very unwell, in pain or at risk of falling during the night.

In these situations, instead of getting out of bed, try to sit up, keep lights dim and do another restful, activity. When you are feeling sleepy again, turn off the lights and go back to sleep.

Spend less time in bed

People who have trouble sleeping sometimes try to catch up on sleep by going to bed earlier or staying in bed longer. But this may lead to worse sleep. Instead, spend less time in bed by changing the times you go to bed and wake up. This can increase your body's sleep drive and help you to get to sleep faster and stay asleep longer.

Develop a good bedtime routine

Routine is really important to set our body clock and help with sleep drive. CBT strategies for a good routine are to:

- Go to bed only when you are sleepy (e.g. when you are yawning, nodding off, and struggling to keep your eyes open).
- Don't go to bed before your usual bedtime, even if you didn't sleep well the night(s) before. This can upset your body clock.
- In the 90 minutes before sleep, try to do things to unwind, quieten your mind, and relax. For example, dim the lights, take a warm bath, have some quiet reading time (outside your bed!).
- Try to get up around the same time every morning, and try not to sleep in, even if you had a bad sleep. This helps to keep your body clock regular.
- Avoid looking at the clock in the middle of the night (this can wake you up even more!). Set an alarm for the morning if needed. Otherwise, let your body and your mind tell you when it is time to get up.



This strategy is useful for people who have insomnia but is not for everyone

It is important to work with a professional (e.g. a psychologist) to work out whether this strategy is right for you. If it is, they can help you to keep track of your sleep each week and adjust your bedtimes and wake-times. Eventually, you will get into a new routine, but this may take 4-8 weeks. Talk to your healthcare team or GP to find a professional to help, if you think this strategy may work for you.

Make your bedroom a place you want to be

It is important that your bedroom is a place where you feel relaxed and want to spend time. Some young people say that their bedroom and bed are places they feel safe during treatment. However, others associate their bed with being sick. If you associate your bed and bedroom with negative feelings, it can help to change the pictures, colours and furnishings. This may help to make your room a place that you associate with being comfortable, relaxed and rested.

Make sure you don't have any negative associations with the things in your environment. Maybe adapt your room and change some things. Use plants and smells that make you feel better and make you feel good.



Write down any changes you can make to your bed, bedtime and bedroom to improve sleep:



A healthy lifestyle for sleep

A healthy lifestyle and good sleep habits can create the best environment for sleep. These recommendations may help both during and after treatment.



Caffeine

Avoid caffeine in the six hours before bedtime. Caffeine is a stimulant which acts to keep you awake. Many things have caffeine, including coffee, tea, chocolate, soft drinks and energy drinks.



Nicotine

Avoid smoking at all! But especially six hours before bedtime. Nicotine is a stimulant that can cause agitation, tension, and disrupted sleep.



Alcohol

Drinking alcohol to help you get to sleep is strongly discouraged. Alcohol causes disturbed and poor quality sleep. Avoid alcohol in the four hours before bedtime.



Food

Feeling too full or too hungry can keep you awake. Having smaller meals across the day can help. Acid reflux or heartburn may also interfere with sleep. Sleeping with extra pillows to prop you up may ease heartburn.



Discuss any issues with a health professional.



Fluids

Avoid drinking too much in the evenings, so you don't need to go to the bathroom at night.



Exercise

Exercise such as walking or yoga helps improve mood and is likely to improve sleep too. Adjust exercise to suit your situation. Very brief and light exercise may be all you can manage if unwell or have physical limitations. Talk to your GP or medical team to discuss what exercise may be helpful for you. Avoid exercise in the two to four hours prior to bedtime.



Towards the end of treatment, I started exercising again and that really helped. I'm still exercising now and that's very helpful for sleep.



Noise

A quiet bedroom and house helps! Ask others to keep the noise down. You can also use ear plugs, or 'white-noise' to drown out other sound. White noise is like the 'shhh' sound a radio makes when it's not tuned properly.

There are heaps of free white-noise apps too (see other resources, page 59).



I use those mindfulness apps with the background music of the beach or waves, or I listen to a guided meditation. If I'm really struggling to sleep it calms me down a lot.



Temperature

Ideally your bedroom should be around 18 degrees - not too hot or too cold.

ZZ Napping

Daytime napping can reduce sleep drive and should ideally be avoided. However, if you are unwell or fatigued, napping may be needed. Try to limit naps to one a day, for no more than an hour, and nap before 3pm. Try to rest instead of napping, but always do this away from the bedroom (remember to keep bed a place for sleep!).



If you can't nap but are tired, other young people recommend... "snacking" "taking a walk" "taking 5 minutes to lie down and focus on your breathing" "chill out" "be by yourself and just relax" or "put the phone away and just breathe"

Light

Bright light is one of the strongest cues for our body clock (this includes sunshine, fluorescent light, lights in most TVs, computers, smart phones and other devices).

In the morning, bright light tells us that it is time to wake up. You can use light to help regulate your sleep. The following tricks can help:

- In the morning, expose yourself to as much bright light as possible (e.g. sit outside)
- In the evening, dim the lights before bed and sleep and sleep in the dark
- If you read before bed, it is better to read under artificial lighting (e.g. a lamp) than from a device or phone
- Try dimming the brightness on your devices (some settings or apps filter-out light).

Establish Routines

Do activities around the same time each day (e.g. walks, naps, meals). Regular routines help your body clock know when it is time to sleep.

Establish a bed-time routine too. In the 90 minutes before sleep, do things to unwind, quieten your mind, and relax. For example, dim the lights, take a warm bath, have some quiet reading time (outside your bed).

BB *My routine has changed my life. From 9:00pm my phone goes to do not disturb and the blue light goes off. I make myself a cup of peppermint tea. I go to the bathroom and get ready for bed. I'm in bed by 9:15-9:30, I read for half an hour, brush my teeth and I am asleep by 10/10:30. I'm also up by 6:30/7 every morning. The difference that has made to me has been amazing.*

BB *Set a bedtime schedule and communicate that with your partner... Yeah, having someone to hold you accountable for your bedtime routine can really help.*



Write down the lifestyle factors you can change to improve your sleep:

Look after your mind and body

Our mind can be super tricky, and is programmed to worry, stress and create anxiety to keep us safe if we experience a threat. If we experience something really stressful, like cancer, the mind can become overactive and keep creating worry, stress and anxiety, even when we don't need it to. Because our thoughts can determine how we feel, this can make us feel awful and can make our body tense. All of this can impact on sleep too. Learning how to look after our mind and body and keep unwanted stress in check is therefore super important. The following strategies can help. It is best to practice these everyday if you can, to manage stress and improve well-being. Like anything, the more we practice, the better we get at relaxing. You can also use these skills when you are stressed or at night if you can't sleep.

Shhhhh... achieving a 'quiet mind'

An 'active mind' is when your mind is busy with lots of thoughts or worries. Some people say their attention jumps from one thought to another. Often our mind also focuses on the past, or the future, rather than what is happening in the moment. This can lead to racing or spiralling thoughts that create stress and make it hard to sleep. The good news is that calming our mind can be achieved by simply focusing our attention.

Focused attention and the power of the breath

The easiest thing to do is focus on your breath. To do this:

- Bring your attention to your breathing. Focus on your chest rising and falling as you breathe. Pay attention to the feeling of your breath as it passes through your nose, down your throat and into your lungs.
- Don't worry if your mind gets distracted by other thoughts. This is very normal. Simply bring your attention back to your breath each time this happens. Over time, you will learn to control your attention better and slow down any racing thoughts.



Try to do this for 10-15 minutes every day.

This helps our mind and body learn to relax but even a few mindful breaths while you are busy or 'on-the-go' can help!

Managing worries

Throughout the cancer journey it is normal to feel a range of difficult emotions including distress, fear, anxiety, loneliness, uncertainty, anger, sadness and worry. This is normal. One problem is that worries and fears can feel 'bigger' or more overwhelming at night, when we are not distracted. This can make it really

hard to sleep. Learning how to manage worries and fears is therefore really important.

Worry time

One strategy that can help is to set aside about 30 minutes each day of "worry time" to focus on concerns or worries. During this time, writing all your worries on a bit of paper and identify which worries are solvable problems (problems you can do something about) and which are unsolvable problems not (problems you have no control over). Make worry time at least 2 hours before bedtime and remind yourself not to worry outside of the time you allocate.

Managing solvable problems...



To identify solvable problems...

Focus on 'can' and 'how' statements. For example, "Can I do anything to change this?" and "How can I make this better?"

Once you have identified solvable problems you can:

- Write down all the things you could do to tackle each worry.
- Brainstorm different ideas and solutions
- Decide on what you can do first (start with the most important and urgent things)
- Break big tasks into smaller steps

- Work out a realistic timeframe to complete each step
- Focus on one step at a time
- Think about who or what could help you complete or achieve each step
- Try not to worry about these outside worry time, when you are in bed or trying to sleep. If you start to worry tell yourself “I have written the problem down and I will work on it tomorrow”.

Managing unsolvable worries

These are usually “why” and “what if” worries about the future. They are far from what is happening here and now and they may not even happen. You can use the skills described in this resource to quiet your mind and relax. To stop these worries, you can also release them using the following strategies:

- **Leaves on a stream.** Imagine yourself sitting next to a stream with leaves floating on the surface. As a worry goes through your mind, put it on a leaf and watch it float away.
- **Thought bubble/cloud.** Imagine your thoughts or worries are like bubbles or clouds coming into your vision and floating away. Just observe them come and go in front of you and try not to respond to or interact with them.



A very common unsolvable worry is “what if my cancer comes back?”

It is natural to worry about prognosis, treatment and the future. As frightening as these thoughts can be, they are simply thoughts and may have no relation to what will actually happen.



Use the strategies for Managing Unsolvable Thoughts to help.



It is important to seek help for emotional concerns if you are struggling

If your emotional health is interfering with sleep, it is important to seek help in addition to using the methods in this resource. You may find it helpful to talk to friends or family, your healthcare team or GP. There are many ways to seek help, and people are often relieved and surprised to hear how normal their experiences are!



See Useful Links and Resources on page 59.

Relax!

Tension, stress, and anxiety are common feelings but especially during and after cancer. Everyone experiences these differently but common signs include:

- Shallow and/or fast breathing or holding your breath
- Tense neck and shoulder muscles
- Tension around your jaw or clenching your teeth
- Tightness in your back, arms, or leg muscles

The problem with physical tension is that it sends 'stress signals' to the brain. This produces chemicals that cause muscles to tense even more, making it difficult to sleep. Learning how to relax is therefore important (but often not as easy as it sounds!).

It can help to become more aware of tension every day. Every now and again, pause and notice the tension in your body. Deliberately relax the muscles and slow down or deepen your breathing. Do this as often as you can during the day, especially when you are stressed or trying to sleep.

Deep breathing

Deep breathing is a very effective way to relax.

- Simply breathe in slowly and deeply, all the way to your belly. Then let your breath out slowly. Some people like breathing in through their nose, and out through their mouth. Do whatever is most comfortable for you.

You can practice this regularly (10-15 mins each day) to help with general relaxation and well-being. You can also use it in bed while trying to fall asleep.

Progressive muscle relaxation

This involves noticing tension in the muscles of your body and relaxing this tension in each part of your body, one part at a time. Start with your head. Focus on any tension and breathe into this space to consciously relax the tension. Then work progressively down your body to your neck, shoulders, through your arms, body, legs and feet. Repeat this as many times as you need to.



Deep breathing is uncomfortable for some people.

This can be the case if you have had certain treatments. If this is the case, try other relaxation methods instead.



Useful resources for relaxation

There are heaps of relaxation tools and resources that can help including books, apps or websites that provide relaxing music and guided relaxation exercises or meditations. You can use these during the day or as you are trying to fall asleep.



See *"Useful Links and Resources"* on page 59.



Write down some mind and body strategies that you can try to improve your sleep:



Track your sleep

It's been really important for me to focus on sleep and getting my sleep hygiene right and a routine in place because otherwise the fatigue is very detrimental to me and my ability to function the next day.

Some people find it helpful to track their sleep each night by keeping notes. This can help you to see patterns and changes over time. If you want to do this, we have provided a sleep tracker at the end of this resource. You can keep a record of:

- The time you went to bed
- The time you wake up
- How many times you wake up each night
- How many hours of sleep you have
- How refreshed you feel when you wake up, or the quality of sleep.



See "My Sleep Tracker" on page 50.

You can also make notes of other aspects of your sleep, or factors that might impact your sleep (for example, whether you had pain or nausea, or how much coffee you drank that day).

If you want to track your sleep:

- Write notes about your sleep as soon as you wake up. It is easy to forget how well you slept.
- Sleep can change from one night to the next (this is normal). Track your sleep over a few weeks or longer to get the best idea of how well you are sleeping.
- Start to notice patterns in your sleep. Track improvements as you tackle your sleep problems using the strategies in this resource.



Some apps and fitness devices can help track sleep but...

Watch out because these can be inaccurate and don't record how you actually experience your sleep. Writing it down can be better.

Medications and herbal remedies

CBT strategies for sleep are known to help reduce the need for sleep medications. CBT is just as effective as medications in the short-term but is more beneficial than medication in the longer-term. Sleep medications may therefore be helpful for short periods of sleep disturbance, or in combination with CBT, while sleep problems start to get better. For some people, ongoing medications for sleep may be suitable, especially if they can't engage in the strategies outlined here.

Medications for sleep

There are many different medications used to help with sleep (including melatonin, anti-depressants, anti-anxiety medications such as Valium, and others). It is important to know that all medications have side-effects. Some can also become addictive or lose their effect if taken for longer than the recommended time. Some medications may also be harmful if stopped suddenly. It is important that you seek advice from your healthcare team or GP about all medications, including those for sleep.

Herbal remedies

There are many herbal remedies or 'over the-counter' medications for sleep, such as valerian, chamomile tea, lavender, kava, hops, or passionflower. While many of these are reported as being helpful, the research is limited. Some herbal remedies can also be harmful if taken at the wrong dose or in combination with other medications. It is therefore important to seek advice from your doctor or pharmacist before using these.

Stop sleep problems coming back

Even the best sleepers have a bad night's sleep from time to time. Sleep problems often also come back, especially during periods of stress or change. If this happens, try not to worry too much. However, it can help to identify early warning signs, so you can do something to improve sleep. Signs might include starting to wake a lot at night or feeling stressed about going to bed. The following questions can help you to put a plan in place to manage.

- What early warning signs will tell you your sleep is getting worse?
- Are there situations in the future you know will impact your sleep?
- What helped you improve your sleep in the past?
- What can you do now to stop sleep getting worse?
- Do you need additional help or support for your sleep problems? Who could give you this help?

Revisit the ideas in this resource as often as you need. Don't be afraid to seek additional help or assistance from your healthcare team or GP too.



Write down your management plan here to identify and manage early warning signs if your is getting worse.

What are the early warning signs for you?

Are there things/events or situations coming up that you know will impact your sleep?

What has helped you improve your sleep in the past?

What can you do to stop your sleep getting worse?

Do you need additional help/support? Who could provide this?



Remember... professionals can help too

This resource covers some of the most important CBT methods for sleep but you may also find it helpful (or more helpful) to use these strategies or improve sleep with a trained professional. They can tailor strategies to you and help with ideas not included in this resource. There are also specialist sleep clinics to help with sleep problems. Ask your healthcare team or GP about appropriate supports and services for you.

Tips for cancer-related problems that impact sleep

Many symptoms or side-effects that impact sleep are outlined earlier in this resource. However, the suggestions here may help you reduce or manage your symptoms and improve sleep.

Hospitalisations

To best manage times when you are in hospital, try to keep your mind active and do as much physical activity as is possible during the day. Reduce these activities in the 90 minutes before bed. Consider using ear plugs and/or eye-masks to help you sleep at night. You can also ask your healthcare team not to wake you if they can avoid it and not to come too early in the morning for their rounds.

BB I made sure my team never turned on the lights all the way when they came to do rounds in the morning so that after they had come through, I'd roll over and go back to sleep

Nausea

It is important to take your nausea medications as recommended (for example regularly, or at the first signs of nausea). When experiencing nausea, it can be to distract yourself (e.g. do crosswords, puzzles or read emails). Relaxation exercises can also help.

Hot flushes / night sweats

Hot flushes and night sweats can cause you to wake often at night and disrupt sleep. Sometimes these are unavoidable but sometimes there are things that can trigger hot flushes or night sweats (such as alcohol or spicy foods). It may be helpful to identify your specific triggers so you can avoid these things. Doing things to help you manage changes in your body temperature can also help. Some suggestions for managing body temperature include:

- Wear cotton as this allows your skin to breathe and temperature to regulate
- Wear layers of night clothes to quickly cool down or warm up and have spare clothes within easy reach if you need to change
- Have layers of sheets/blankets at night that can be easily adjusted to suit changes in body temperature
- Use towels to help absorb sweat
- Adjust your bedroom temperature to suit

- Keeping these near your bed may help you to cool down too:
 - a cool drink
 - a water spray bottle
 - a hand-held or electric fan
 - an icepack or cooling pillow
 - a small bucket of water and flannel.



Remember, it is important to discuss symptoms with your health care team as there may be medication that can help and they can refer you to a specialist if needed.

Urinary changes (changes in how you wee)

Urinary changes and symptoms may include:

- Needing to urinate many times during the night ('nocturia')
- Needing to urinate many times during the day ('frequency')
- Difficulty controlling when you urinate ('leakage')
- The sudden need to urinate ('urgency')
- Trouble passing urine ('difficulty')
- Trouble getting started ('hesitancy').

These problems can wake you up often and lead to longer periods of being awake at night. If this is a challenge for you, speak to a health professional about lifestyle changes

and treatment options. Medication may be recommended in some cases. You can also:

- Think about when you drink fluids and how much fluid you drink. It is a good idea to avoid having large quantities of fluids after dinner. Drinking caffeine and alcohol late at night will also make the problem worse.
- Go to the toilet before going to bed
- Have a urine bottle/bedpan near your bed to minimise the need to get out of bed to go to the toilet and/or wear an appropriate pad at night
- Keep warm layers/slippers near your bed for easy trips to the bathroom
- Wear easy to remove clothes in case you need to go to the toilet in a hurry.

Bowel changes

Some cancers or treatments may lead to changes in bowel function. Diarrhoea can result in frequent trips to the toilet through the night. This can be very disruptive. Constipation can also cause increased discomfort or pain. Any changes in bowel function should be discussed with your healthcare team or GP as some issues can be managed through changing fluid and food intake. Medication may also be needed.

Dry mouth

Dry mouth can occur during and/or after treatment. To help, you can keep water by your bed or use a water spray or ice-cubes to wet your mouth. There are also products that can help (e.g. mouth washes) so speak to your healthcare team about this too.

Shortness of breath

Shortness of breath may be caused by medical factors, stress or anxiety. Lifestyle factors can also result in shortness of breath, such as eating full meals just prior to bed. You can avoid things that contribute to shortness of breath at night and try the following:

- Try taking slow and deep breaths in through the nose, and slow breaths out through the mouth
- Position your pillow to maximise comfort
- Raise the head of your bed. This can increase comfort and help minimise stress and anxiety too.



See “Looking after your mind and body” on page 29 for ideas that may be useful.

Steroid medications

Steroid medications including dexamethasone, prednisolone or hydrocortisone, may be used to prevent nausea or as part of some treatments. They can have a stimulating effect and may make you more alert and awake. The best time to take your steroid medication is first thing in the morning (after some food) to minimise the impact on sleep. It may be helpful to accept that sleep may be disrupted to some degree when taking steroids. Instead of trying to force sleep, plan to engage in restful activities outside of the bedroom when you can't sleep. If sleep is a major problem when on steroids, you can discuss trying different medication options with your doctor.

Pain

Pain is a common reason for poor sleep. While pain can sometimes be difficult to get rid of, there are many things that can help you to manage pain. These include:

- Talking to your doctor about the best pain medications to use, and the best time to take medication to help with sleep
- Set-up your bed to minimise pain (for example, extra pillows or a comfortable mattress)
- Have pain medications and water by your bed in case you need to take an extra dose overnight
- Discuss other ways to help manage your pain with your healthcare team, for example, heat packs, spiky balls or muscle stretches.

Better ways of thinking about pain or discomfort

There are a range of uncomfortable side effects and physical feelings can come with cancer including pain, nausea, hot flushes, dry mouth, skin rashes or itches, tingling or numbness in hands or feet and fevers. How you think about these uncomfortable feelings can change how much pain or discomfort you feel. The following CBT tips can help you change your thinking and sleep better.

Our natural response to pain and discomfort is to think 'this feels terrible', and we want to push the feeling away. When it doesn't go away, we might get upset and frustrated, making sleep harder. This is a normal response. However, instead of calling a feeling 'pain' or 'nausea' or 'discomfort' in your mind, try calling it a 'sensation'. Remind yourself that the sensation might not be pleasant, but that it is just a sensation.

TIP 1:

Whenever you notice unpleasant physical feelings, try to notice unhelpful thoughts such as :

- 'I hate feeling this way'
- 'Oh, not again...'
- 'This will never end...'

Try to reframe these thoughts or think about them in a different way. For example, you may think:

- 'I've felt like this before and I have managed OK'
- 'I don't like feeling like this, but I know that it won't last forever.'

Try to notice these physical sensations without labelling them as 'terrible' or 'bad'. Remind yourself that reacting negatively to these feelings can make them bigger than they need to be.

Tip 2:

Practice being patient with your pain or discomfort. Instead of wishing the pain or discomfort away, imagine each breath of air you take as flowing into and around the feeling.

As you breathe in, imagine creating space around the feeling. You could say something like: 'This sensation is uncomfortable. I don't like it, but I do have room for it.'

Tip 3:

Treat unpleasant feelings the same way you treat muscle tension. As you breathe, let go of tension around that area.



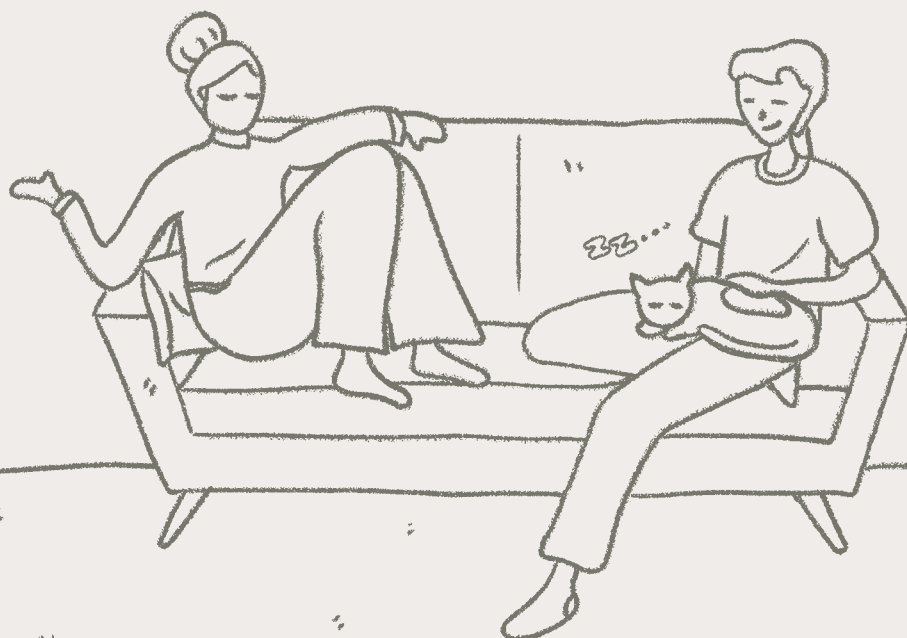
See "Relax" on page 32 for tips on muscle relaxation.



Write down treatment and side-effects that are impacting your sleep here:

Write down a few key things you could do to try and improve your sleep here:

Information for others...



Information for parents, carers, partners, siblings and friends

Whether you are a parent, carer, partner, sibling or friend of a young person who has cancer, there are things you can do to help with sleep. Some tips include:

- Familiarise yourself with the common impacts of cancer on sleep
- Familiarise yourself with the practices that support sleep and the strategies in this resource so you know what can help and improve sleep
- Ask the young person about their sleep
- Check in regularly about sleep quality and energy levels
- Talk about setting a clear bedtime routine for everyone at home so that it becomes usual practice, and everyone knows what to expect when it comes to bedtime in your house
- Support good sleep practices and offer encouragement
- Offer to keep others accountable for the bedtimes and bedtime routine they set
- Know what works for your sleep and what doesn't and model good sleep behaviours.
- Don't be afraid to ask for help! Ask a medical professional if you are not sure what to do.

Information for health professionals

 *During treatment the nurses were good, they would literally tell the doctors not to turn on the lights and wake me up. With the adolescents they were like don't walk in at 7 in the morning, walk in at 10...so you still got that sleep if you needed it. It definitely made a difference.*

This resource is a self-management guide to CBT based approaches for treating insomnia and other sleep disturbance in people with cancer. Young people can use this resource on their own, however they may gain more by involving a health professional in their efforts to improve sleep.

Screening for insomnia symptoms

All health professionals can play a role in identifying and normalising sleep problems such as insomnia. Regularly asking young people about their sleep, or screening with a questionnaire can be useful both during and after cancer treatment. A score of 8 or above on the Insomnia Severity Index (© Morin, C.M. 1993, 1996, 2000, 2006) is a useful indicator of sleep problems that may be helped by use of this resource.

Health professionals can also help by screening for and addressing other mental or physical health problems that impact sleep, including medical sleep disorders such as sleep apnoea or restless legs syndrome. Health professionals can then offer appropriate intervention and support. Where medical sleep disorders are suspected, referral (by a medical practitioner such as a GP) to a specialist sleep clinic is recommended. Medical sleep disorders should be explored prior to, or alongside, the use of this resource.



Supporting good sleep and advocating for young people

Health professionals should understand the developmental needs of young people, including the fact that biologically, the sleep needs and sleep/wake routine for young people differs to those of younger children or older adults. Professionals can support better sleep for young people while in hospital by identifying sleep preferences, working to accommodate these and advocating for young people's needs with other team members. Professionals can offer support and should apply principles and practices of quality youth care in assessment and care planning with young people with cancer, including in relation to sleep, both during and beyond cancer.

Use of this resource

Professionals can assist young people in the use of this resource in the following ways:

- Determining if this resource is relevant for young people (see page 5)
- Helping to identify the most useful sections of this resource for each young person
- Offering periodic review appointments (for example, 3 and 6 weeks after the person starts using this resource), to review progress, troubleshoot new challenges and barriers to change, and provide encouragement and support
- Assessing lifestyle habits and treating cancer-related problems that may be causing or contributing to night-time sleep difficulties
- Providing advice and guidance on the use of CBT and pharmacological interventions for insomnia or other sleep problems
- Providing a referral to a specialist in sleep (such as a psychologist) if sleep problems do not improve after use of this resource and support provided.

The last word:

Take home messages



Sleep is really important. It is essential for our health, wellbeing, learning, memory and concentration. Sleep is especially important to help our body recover after cancer.

BB Learn to love your sleep. It is going to help you heal, it is going to reenergise you. Sometimes we avoid sleep because we don't want to miss out. But if you are fatigued, you are going to miss out more because you are not going to be present.

Cancer and treatment can have lots of impacts on sleep from the time of diagnosis, throughout treatment and beyond the end of treatment.

BB Before cancer I was more or less on top of sleep. I was conscious of sleep hygiene. So, I tried carrying that over after I was diagnosed but it just sort of went out the window... like everything else.

Everyone's experience is different. Try not to compare yourself to others. Work out what you need for your own health and wellbeing!

BB Listen to your body. Don't compare yourself to others. You have your own needs and everybody else has their own needs.

BB You really need to advocate for yourself. We all have unique journeys, and we all learn what our bodies need and we all become very in tune with that so it is often us having to advocate to say 'this is how I am feeling'.

Identify sleep problems early. This way you can do something about them, try strategies to improve sleep and ask for help if you need to.

BB Being honest with yourself and your situation because how you are feeling about sleep is important.

It takes time to recover. So be kind to yourself, adjust your expectations and take your time!

Recovery is such a long journey. It's about taking it step by step, acknowledging the differences that you make every day and recognising how much of an impact you have on your mental health and wellbeing and your physical self too. I think that's really important.

Ask for help and remember that there is no such thing as a silly question. When it comes to your health, it is important that you understand information, what is going on and have all your questions answered – so don't be afraid to speak up.

A lot of the things you go through health- and mental health-wise, you can get help for those. Know that it is ok to ask for help.

Be your own best friend & trust yourself. It is important to remember that it is your health and your life and that you are in control. You are also the expert in terms of your health. Your GP and health care team are there to support you, so back yourself – you've got this.

Listen to your body and if you are ever feeling guilty or really judgemental of yourself, think to yourself... if I was to say this to someone else with cancer how would that make them feel? And then I cut that out!

Treat yourself the way that you treat someone you love the most.

More...



My Sleep Tracker

Name: _____ Date: _____

IMPACTS ON SLEEP	
<i>It can really help to identify the things that impact on your sleep so you can change the things that you want to and improve your sleep</i>	
Category	Impacts (list them here)
Physical/Health e.g. current diagnoses, treatments or medication and side effects, symptoms, concerns or needs	e.g. pain, medication that makes you sleepy or keeps you awake or having to go to the toilet a lot!
Worry/stress e.g. things that are worrying me or causing me stress or anxiety	e.g. school, work, relationships, worry about cancer, worry about the future or a racing mind etc.
Social factors e.g. social things that impact on sleep	e.g. irregular work or study hours, socialising with friends, too much screen time (be honest!) or gaming.
External factors e.g. things at home/in the environment that impact on sleep	e.g. an uncomfortable bed, noise at home, having other people around, sharing a room etc.

IMPACTS ON SLEEP

It can really help to identify the things that impact on your sleep so you can change the things that you want to and improve your sleep

Category	Impacts (list them here)
Other e.g. anything else!	

SLEEP GOALS

It can really help to identify your sleep goals so you can monitor the effect of any changes you make to try and improve sleep.

Hours of sleep

I need _____ hours of sleep a night (on average).

How I want to feel

I want to feel _____ when
I wake up. Over the course of a week I want to feel
_____.

SLEEP STRATEGIES

It can help to clearly identify the sleep strategies that you are going to try to improve your sleep.

SLEEP MAP

It can help to map or record your sleep so you can identify any patterns and judge whether the strategies you are using are effective to improve your sleep.

Question	Day 1 (Mon)	Day 2 (Tue)	Day 3 (Wed)	Day 4 (Thur)	Day 5 (Fri)	Day 6 (Sat)	Day 7 (Sun)
What time did you wake up this morning?							
What time did you get into bed tonight?							
What time did you try and go to sleep?							
How long did it take you to fall asleep?							
How many times did you wake during the night?							
How long were you awake for (mins)?							

SLEEP MAP

It can help to map or record your sleep so you can identify any patterns and judge whether the strategies you are using are effective to improve your sleep.

Question	Day 1 (Mon)	Day 2 (Tue)	Day 3 (Wed)	Day 4 (Thur)	Day 5 (Fri)	Day 6 (Sat)	Day 7 (Sun)
How many hours of sleep did you get?							
How would you rate your sleep quality? (0 - 10 (excellent))							
Very good							
Good	☐	☐	☐	☐	☐	☐	☐
Ok	☐	☐	☐	☐	☐	☐	☐
Bad	☐	☐	☐	☐	☐	☐	☐
Very bad	☐	☐	☐	☐	☐	☐	☐
Did anything disturb you or wake you up?							
Did you try any strategies? What were they and how well did they work?							

Notes

[illegible]

Glossary

TERM	DESCRIPTION
Allied Health	The range of professionals who are not doctors or nurses but provide healthcare. May include dentists, psychologists, social workers, occupational therapists, physiotherapists, dieticians, exercise physiologists etc.
Anxiety	An emotion characterized by feelings of tension, worried thoughts and physical changes. Anxiety disorders are also a common mental illness. People with anxiety disorders usually have recurring intrusive thoughts. They may avoid certain situations due to worry. They may also have symptoms such as sweating, trembling, dizziness or a rapid heartbeat.
AYA	Adolescent or young adult. Usually refers to people aged 15-25 years.
Cancer	A group of diseases characterised by the multiplication & uncontrolled spread of abnormal cells.
Can-Sleep	A resource developed to improve sleep for adults with cancer.
Care Plan	A plan that enables you and your GP or health care professional to best agree on and manage your care.
Cognitive	Relates to the brain, how we learn things and behaviour.
Cognitive Behavioural Therapy (CBT)	A form of psychological treatment that helps to change unhelpful thoughts, behaviours and actions. CBT can be helpful for several problems, including sleep.

TERM	DESCRIPTION
Chemotherapy	A form of cancer treatment that uses medication to treat cancer.
Consultation	Another name for the meeting or appointment with a GP or health care professional.
Daytime sleepiness	A common sleep disorder often resulting from sleep deprivation, interrupted sleep and medications which cause sleepiness.
Depression	A common mental illness characterised by persistent sadness, a lack of interest or pleasure in previous enjoyable activities and disruption to sleep or appetite.
Dexamethasone	A steroid sometimes used to treat cancer.
Diagnosis	The identification of the nature of a health condition or illness by examining symptoms.
Fatigue	Extreme tiredness resulting from mental, physical effort or illness.
GP	General practitioner or doctor who is a general health specialist and provides general medical care, mental health care, sexual health and social health care and support.
Health	Your physical, mental and social wellbeing.
Health care Professionals	Professionals that provide care for physical, mental and social health.
Health care Team	Team of people involved in caring for your health. Includes you, family and friends as well as professionals that may include your GP, specialists (e.g. oncologists), nurses, dentists, allied health professionals and other supports.

TERM	DESCRIPTION
Hormone Therapy	The use of hormones to treat cancer, especially breast, ovarian and prostate cancers.
Late Effects	Long term impacts of treatment which can occur five years and longer from the completion of treatment.
Mental Health	Health relating to psychological and emotional wellbeing.
Mental Health Care Plan	Plans provided by your GP to give access to mental health care. Mental Health Care plans provide free or subsidised access to mental health professional support for 10-20 sessions per year.
Oncology	The study & treatment of cancer.
ONTrac at Peter Mac	Victorian Adolescent & Young Adult Cancer Service.
Physical Health	The health of your physical body and how it functions.
Radiotherapy	A form of cancer treatment that uses radiation.
Referral	Made from one health care professional to another for consultation, review or further action, treatment or care.
Restless Legs Syndrome	A condition that causes an uncontrollable urge to move the legs. It usually happens in the evening or when lying down. It can be very disruptive to sleep.

TERM	DESCRIPTION
Scan	Creating a visual representation of a part of the body. It is usually used to diagnose a condition. Some types of scans or imaging include X-Ray, ultrasound, ECG, MRI or CAT scans.
Sleep	Night-time rest that is essential for our physical and mental health and wellbeing.
Sleep Apnoea	A sleep disorder in which breathing repeatedly and uncontrollably starts and stops, causing snoring and tiredness.
Sleep Disturbance	A name for disorders which impact initiating and maintaining sleep.
Social Health	Health relating to your interaction with the world, other people, systems and organisations and society.
Steroids	Treatments using man made hormones that can disrupt sleep.
Symptoms	Physical or mental features or signs of a condition, disease or illness.
Young Person	Usually refers to people aged 15-25 years.

Useful Services, Links & Resources

SERVICE	DESCRIPTION
Australian Psychological Society	Information about psychology support services and how to find a local psychologist in your area.
BeyondBlue	Mental health information & support.
Cancer Council	A wide range of free resources, such as fact sheets and phone supports. You can call the Cancer Council on 13 11 20 for cancer information and support too.
CanTeen	Information for young people with cancer & their families, peer support, advocacy & research.
Headspace	Australian national youth mental health service providing support, care, information & resources for people aged 15-25 years.
Headspace Meditation App	A useful app for guided meditation and relaxation.
Smiling Mind Mindfulness App	A useful free app for mindfulness exercises.
Health Engine	A website intended to help people navigate the Australia health care system. Includes searching for GPs in your local area.
Insight Timer	A free app that is great for guided meditations and soothing music which can put you to sleep and shuts off when the session ends.

SERVICE	DESCRIPTION
Kids Helpline	Phone & online counselling service for young people aged 5 – 25 years. Available 24/7. Call 1800 55 1800
Lifeline	A national charity for all Australians experiencing personal crisis. 24/7 crisis support & suicide prevention services. Call 13 11 14
Livewire	An online community of support for young people aged 10-20 years living with chronic illness or disability.
National Sleep Foundation	Useful information and strategies for sleep: www.sleepfoundation.org
ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service	Provides expert multidisciplinary care & support to young people & families including medical support, psychology, social work, education & vocation support & other specialty care.
Sleep Health Foundation	Useful information and strategies for sleep. The website also provides a service that helps you to find an appropriate sleep service near you.
Sleep Hub	Australian information and useful resources for sleep.
The Better Health Channel	Useful information about health and sleep.
Youth Cancer Services	Services in each state of Australia that provide expert care & support to young people & families including medical support, psychology, social work, education & vocation support & other specialty care.

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Note to reader: We hope that this resource helps you to improve your sleep, no matter where you are at in terms of the cancer trajectory. This resource is a general guide. It is not a substitute for expert medical or psychological advice. All care was taken to ensure that the information was accurate at the time of publication.

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More Information: For more information please contact the Can-Sleep team: Phone (03) 8559 5265 or E-mail: CanSleep@petermac.org.

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