CAN-SLEEP: MAKING NIGHT-TIME SLEEP PROBLEMS GO AWAY

Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

A guide for people with cancer

CAN-SLEEP

This Can-Sleep booklet was written and developed as part a collaborative project to address cancer survivors' night-time sleep difficulties. Contributors have included members of the Can-Sleep Project Team and Steering Committee, as well as clinicians, staff and consumers from Peter MacCallum Cancer Centre, Royal Melbourne Hospital, Royal Women's Hospital, Monash University, The University of Melbourne and the Australian Cancer Survivorship Centre, a Richard Pratt legacy.

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CAN-SLEEP PROJECT TEAM:

Dr Maria Ftanou
Head Clinical Psychologist, Peter Mac

Ms Justine Diggens
Senior Clinical Psychologist, Peter Mac

Dr Dani Bullen
Clinical Psychologist and Project Manager, Peter Mac

Prof Steve Ellen
Director Psychosocial Oncology Program, Peter Mac

A/Prof Jeremy Goldin
Senior Sleep Physician, Royal Melbourne Hospital

Mr Tom Minogue
Head Sleep Scientist, Royal Melbourne Hospital

Dr Kirk Kee
Sleep Physician, Royal Melbourne Hospital

Dr Jo Phipps-Nelson
Manager, Cancer Experiences Research, Peter Mac

Dr Michaela Pascoe
Cancer Experiences Research, Peter Mac

Ms Jin Joo Lee
Project Officer, Peter Mac

Ms Trista Koproski
Data Manager, Cancer Experiences Research, Peter Mac

Ms Allison Drosdowsky
Cancer Experiences Research, Peter Mac

Dr Lesley Stafford
Head of Clinical Psychology, Royal Women's Hospital

Dr Elizabeth Barson
Senior Clinical Psychologist, Royal Melbourne Hospital

Ms Kate Willcox
Senior Clinical Psychologist, Royal Melbourne Hospital

A/Prof Justin Tse
Director of Medical Student Education, St Vincent's Clinical School & Melbourne Medical School, University of Melbourne

Mr Wallace Crellin
Consumer Consultant

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CONTENTS

INTRODUCTION

Is this booklet for you? 1

What is Cognitive Behavioural Therapy for sleep? 2

How do you use this booklet? 2

How long before sleep gets better? 2

ALL YOU NEED TO KNOW ABOUT SLEEP AND CANCER

Why do we sleep? 3

Factors that impact sleep: 3

Sleep disrupting factors: 4

Sleep deprivation 4

The vicious cycle of sleep problems 4

Insomnia 5

WHAT CAN HELP IMPROVE SLEEP?

1. Developing healthy thoughts about sleep 6
2. Keeping bed a place for sleep 8
3. Spending less time in bed 9
4. A healthy lifestyle for sleep 10
5. Tips for cancer-related problems that impact sleep 12
6. Looking after your mind and body 16
7. Tracking your sleep 20
8. Medications and herbal remedies for sleep 20
9. Stopping sleep problems from coming back 21
10. Additional treatments and resources for sleep 22

INFORMATION FOR HEALTH PROFESSIONALS

1. Helping cancer patients with sleep problems 23
2. References and further reading 24

INTRODUCTION

Sleep problems are extremely common in people with cancer. They include short-term sleep disturbance (which may be caused by cancer treatment or side-effects), or longer-term sleep problems such as insomnia. You may have insomnia if you often find it hard to fall asleep or stay asleep. We know that as many as 6 in 10 cancer survivors have problems of insomnia, which is up to three times the rate found in the general population. As such, sleep problems are a big problem for people with cancer, and sleep problems often impact well-being. The good news is that there are many things that you can do to improve your sleep.

Is this booklet for you?

This booklet can help people:

- improve existing sleep problems
- cope better when new sleep problems arise or
- prevent sleep problems worsening.

This booklet provides ideas that people can use to manage their own sleep. Some people may find it more beneficial to work on sleep problems with the help of a health professional. At the end of this booklet (page 23) there is a section for health professionals on how they can work with you to address your sleep concerns. Involving a health professional may be particularly important if your sleep is impacted by:

- ill health
- distress
- medication effects
- alcohol effects
- drug effects.

Sleep problems can sometimes be a sign of emotional difficulties such as anxiety or depression. If you think this may be the case for you, you should discuss this with your medical team or GP.

This booklet is not designed to address problems such as:

- 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 legs syndrome.

These conditions need different treatments than those included in this booklet.

What is Cognitive Behavioural Therapy for sleep?

This booklet contains a range of helpful tools and tips to help people with cancer regain some control over their night-time sleep. These methods are referred to as Cognitive Behavioural Therapy (CBT).

To bring positive change, CBT looks at our:

- thoughts and beliefs (cognitions)
- our feelings (emotions)
- and our actions (behaviour).

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

While sleep medications can be useful for short periods of time, they carry the risk of side effects and addictions. CBT is safer and may lead to longer lasting improvements in sleep. CBT is recommended as the first-line treatment for problems such as insomnia.

How do you use this booklet?

There are usually many factors that impact a person's sleep. It is therefore best to use a range of different approaches to improve your sleep. This booklet outlines many ideas for you to consider and try.

Pick the approaches that seem most relevant (and do-able) for you. You may find all the sections useful, or you may find only one or two sections seem useful for your situation. This is OK. Everyone is different.

You can read this booklet and make changes in one go. You can also read different sections over a number of weeks, and try making changes as you go.

How long before sleep gets better?

It can take a number of weeks (or longer) before you notice any improvements in your sleep, so don't give up. The longer you have had a sleep problem, the longer it might take to see improvements.

ALL YOU NEED TO KNOW ABOUT SLEEP AND CANCER

Why do we sleep?

All creatures need to sleep. Sleep helps us regain our energy and repair our bodies. Sleep also helps our brains process information, store memories and learn. Without adequate sleep we have trouble concentrating and feel fatigued.

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 briefly a number of times over the course of a night's sleep.

Factors that impact sleep:

Sleep drive ('hunger' for sleep)

Sleep drive is like hunger. It increases over the course of your day as you stay awake longer. A high sleep drive at bedtime helps you fall asleep faster, and stay asleep longer. Napping during the day will reduce your sleep drive, and may make it hard to fall asleep at night time.

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 go to sleep. The body clock is 'set' by various signals in our environment. The most powerful signals are light (signalling time to be awake) and darkness (signalling time to sleep).

A quiet mind

An active mind at bedtime 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. Particularly difficult times may include initial diagnosis, when receiving test results, or times of illness or change.

See "Looking after your mind and body" on page 16 for more information on how to strengthen your quiet mind.

Sleep disrupting factors:

- External factors that disrupt sleep can include noise, shift work, or parenting responsibilities.
- Factors that impact our health and body functioning can also disrupt sleep. These include cancer, and cancer treatments, such as surgery, chemotherapy, radiation therapy and medications such as steroids. There are also many treatment side-effects that impact sleep. Common side-effects include pain, nausea, hot flushes/ night sweats, or urinary changes.

See "A healthy lifestyle for sleep" on page 10 and "Tips for cancer-related problems that impact sleep" on page 12 for ways to manage these problems.

Sleep deprivation

Sleep deprivation occurs when we are not getting enough sleep. We can experience a range of problems when we aren't getting enough sleep, including:

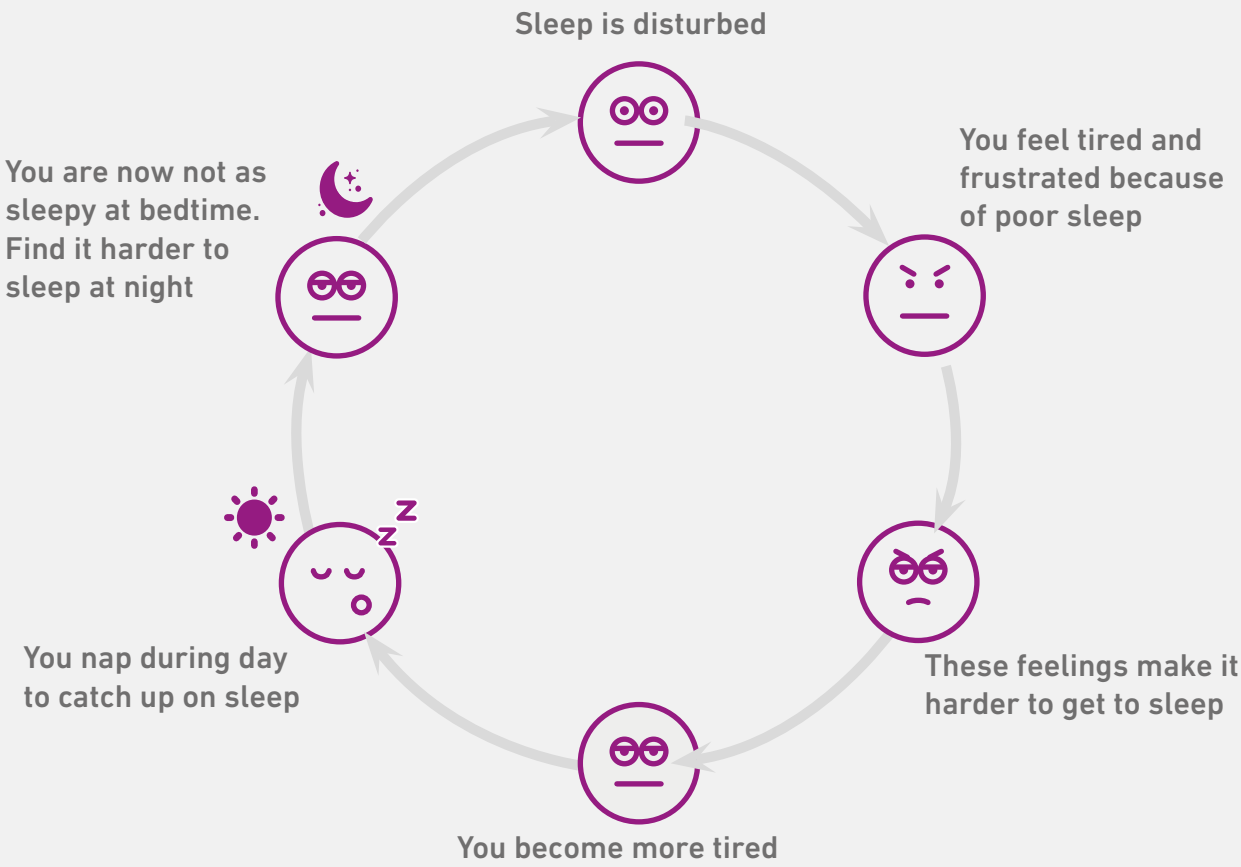
- poor concentration
- poor memory
- low energy
- fatigue
- irritability
- tearfulness
- difficulty thinking clearly or making decisions
- lowered ability to cope with pain, illness, or stress.

It is important not to worry too much about sleep deprivation. Brief periods of sleep deprivation are a normal experience in life. Our bodies are good at catching up on important stages of sleep after a period of sleep loss. For example, after long periods of sleep loss, one or two nights of sleep can restore our body close to normal.

The vicious cycle of sleep problems

The challenge with sleep problems is that the way we respond to a loss of sleep can sometimes worsen the sleep problem, or keeps it going over time.

For people who have cancer, there are many cancer-specific factors that can trigger or worsen sleep problems. It is quite normal to feel worried or concerned about how much sleep you are getting. It is important to know that many sleep problems are temporary, and will get better on their own. However, it is also the case that sometimes the vicious cycle of sleep can keep a problem going, or make it worse. Prevention is better than cure, so thinking about making small changes early makes sense.



Insomnia

With insomnia, sleep is difficult even when you have the right conditions for sleep. For example, falling asleep or staying asleep will be difficult even when you are sleepy, comfortable, or in a quiet environment.

Signs of insomnia include:

- difficulty falling asleep
- waking up in the middle of the night or too early
- having difficulty falling back to sleep
- feeling unhappy with the amount or quality of sleep you are getting
- daytime problems, such as fatigue or difficulty concentrating
- distress or anxiety about not sleeping well.

Insomnia can occur for short periods of time (days or weeks). Insomnia can also go on for longer periods of time (months or years).

If you believe you have insomnia, the most important sections of this booklet will be:

"Developing healthy thoughts about sleep" on page 6

"Keeping bed a place for sleep" on page 8

"Spending less time in bed" on page 9

Try to also work on at least one skill from"Looking after your mind and body" on page 16.

WHAT CAN HELP IMPROVE SLEEP?

1. DEVELOPING HEALTHY THOUGHTS ABOUT SLEEP

Firstly, it is important to bust a few myths about sleep.

Myth

'I need 8 hours 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 in 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.

You may notice other thoughts that cause you to worry about your sleep. For example, *'If I don't sleep properly, it is bad for my health. My cancer will get worse or come back'.*

- Try reminding yourself that our bodies are designed to cope and adjust to sleep loss. If our sleep is shorter (fewer hours) we move into the deep stages of sleep more quickly (the important stages of sleep).
- Try telling yourself: *'Worrying isn't going to help. I need to trust my body to get the sleep I need'.*

Write down some of your unhelpful thoughts and beliefs about sleep here:

Can you think of a more helpful way to think about your sleep? Re-write your new thoughts and beliefs here:

2. KEEPING BED A PLACE FOR SLEEP

If you have not slept well for a while, you may be spending a lot of time in bed awake. The body can then learn to be awake when in bed, instead of being asleep. This is a common problem in insomnia.

This section is about CBT methods that re-train your body to sleep when in bed, rather than be awake. These CBT methods are some of the most important tools for improving sleep, especially if you have insomnia. They are about limiting your time in bed to times you are actually sleeping and removing frustration and stress from your experience. This re-trains your mind to link your bed and bedtime with sleep (not frustration). This allows your body to feel relaxed and calm when going to bed, so you can achieve the sleep you would like.

While sleep is important, bed is also a place for intimacy and sex. It is OK to cuddle, kiss, and have sex in the bedroom, but try and take all other activities, like reading and TV, outside the bedroom so that it is mainly a place for sleep.

Some of the steps below may feel like they will be unhelpful (for example, getting out of bed in the middle of the night), but they are very effective, so please persist.

Get out of bed (and leave the bedroom) if unable to sleep

This idea is very helpful if you have trouble falling asleep, or falling back to sleep.

- If after about 20-30 minutes of trying to fall asleep you are still feeling awake (not dozy or close to sleep) - stop trying. If you keep trying hard to sleep in these situations, you might feel more frustrated, which makes it even harder to sleep.
- Instead, after 20-30 minutes (avoid looking at the clock. Your best guess is okay):
  - get out of bed
  - go into another room
  - do something quiet and relaxing (See page 11 for tips about using phones or tablet devices)
  - try to stay calm and relaxed
  - remember that with every passing minute that you are awake, your body is becoming sleepier
  - when you next feel sleepy, go back to bed and try again.

You might need to do this many times a night, and this is okay. You may feel more tired when first trying this approach, however research has shown that it is very helpful in overcoming insomnia, so don't give up.

Does this tip apply to you?
This approach is not suitable during periods of hospitalisation or if you are very unwell. It may also not be ideal if you are at risk of falls during the night, or if getting out of bed worsens pain. In these situations, instead of getting out of bed, sit up, keep lights dim and engage in other, restful, activities. When feeling sleepy again, turn off the lights and go back to sleep.

Other CBT ideas that support your body clock and sleep drive

- Go to bed only when you are sleepy (that is, yawning, nodding off, and struggling to keep your eyes open).
- Do not go to bed before your usual bedtime, even if you didn't sleep well the night(s) before. Going to bed too early can upset your body clock.
- Get up around the same time every morning, and try not to sleep in, even if you had a poor night's sleep. This helps keep your body clock regular.
- Avoid looking at the clock in the middle of the night (this will only 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.
- Keep your bed for sleep or intimacy only. Avoid eating, watching TV, reading or working in your bed or bedroom.

3. SPENDING 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. If you have insomnia (see page 5), this may actually lead to more broken sleep that is not of good quality. Instead, it might be better to spend less time in bed. This can be done by changing your bed-time and wake times. Giving yourself less time in bed each night to sleep may increase your body's drive (need) for sleep. This will help you get to sleep faster and stay asleep longer.

Cutting back on the time you spend in bed is an effective way of treating insomnia. It should be done under the guidance of a trained health professional (such as a psychologist) who is experienced in CBT for insomnia. This professional will work with you to decide on what time to go to bed and what time to wake up. To help improve your sleep, they will help:

- keep track of your sleep each week
- adjust your bed-times and/or wake-times.

Usually you will spend less time in bed at first (for example, moving your bed-time to a later time in the evening). You may feel sleepier than usual at first. This is normal. Within a few days, the quality of your sleep should start to improve. Each week your sleep improves, you can give yourself a little more time in bed. Eventually, you will get to a new bed-time / wake-time routine that feels right. This may take 4-8 weeks.

Note: Spending less time in bed is a useful treatment for many people who suffer from insomnia, but it is not for everyone. We encourage you to work with a professional who is experienced with CBT as a treatment for insomnia, to make sure it is right for you.

4. A HEALTHY LIFESTYLE FOR SLEEP

A healthy lifestyle and good sleep habits can help create the best environment for sleep. These recommendations may help both during and after treatment for cancer. When people are experiencing sleeping difficulties, it is recommended they try the following:

Caffeine

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

Nicotine

Avoid smoking six hours before bedtime. Nicotine is a stimulant in cigarettes that can cause agitation, tension, and disrupted sleep.

Alcohol

Drinking alcohol to help you get to sleep is strongly discouraged. Although alcohol may be relaxing, it actually causes disturbed and poor quality sleep. Avoid alcohol in the four hours before bedtime.

Food

Feeling too full or too hungry can make you feel awake. Smaller meals spaced out across the day may be more helpful. Acid reflux or heartburn may also interfere with sleep. Discuss any issues with a health professional. Sleeping with extra pillows to prop you up may ease heartburn.

Fluids

Avoid drinking too much in the evenings, to avoid the 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 will be helpful for you. Avoid exercise in the two to four hours prior to bedtime.

Noise

A quiet bedroom and house helps with sleep. Consider using ear plugs, or 'white-noise' to drown out other sounds. White-noise is like the 'sh' sound a radio makes when not tuned to any channel. There are many free white-noise apps on smart phones. Discuss noise in your house with your partner or house-mates, and ask for their help in keeping noise down.

Temperature

Ideally the bedroom should be around 18°C; not too hot or too cold.

Napping

Daytime napping reduces your sleep drive (hunger for sleep), and ideally should be avoided. However, if unwell or fatigued, napping may be needed. Try to limit naps to one a day, for no more than an hour, and before 3pm. Try to rest instead of napping, but always do this away from the bedroom (bedroom is for sleep only).

Establish a bed-time routine

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

Keep regular routines

Do activities around the same time each day (for example, walks, naps, meals). Regular routines help your body clock know when to expect sleep.

Light

Bright light is one of the strongest cues for our body clock (this includes sunshine, fluorescent lights, and LED lights in most TVs, computers, smart phones and other electronic devices). In the morning, bright light tells your body that it is day time. This helps you feel more awake and alert.

- In the mornings, expose yourself to as much bright light as possible.
- Light lamps or light therapy glasses can be bought, to use when you wake up.
- In the evenings, keep lights dim before sleep.
- Sleep in darkness.
- For people who enjoy reading before bed, it is better to read a book under artificial lighting (eg. a lamp) than reading from electronic devices that give off light, such as iPads®, tablets, e-readers or smart phones. However, don't be too worried about using electronic devices in the evenings or overnight. They can be a useful distraction from worries, and are often relaxing and a useful source of enjoyment.
- Try dimming the brightness on your devices (some settings or apps filter-out light). Try to avoid watching or reading things that make you feel more awake (such as an action movie).

Write down a few things you could change to improve your sleep here:

5. TIPS FOR CANCER-RELATED PROBLEMS THAT IMPACT SLEEP

Most people with cancer will experience symptoms or side-effects related to their cancer or treatment. Many of these can impact sleep. While some side-effects or symptoms may be unavoidable, the suggestions here may help you reduce your symptoms, or make them easier to put up with. It is also important to talk to your treating health professional about your side-effects, for assessment, advice and management.

Hospitalisations

Try to keep your mind active and do as much physical activity as is possible during the day. Reduce these activities in the hour and a half before bed. Consider using ear plugs and/or eye-masks to help sleep at night.

Nausea

It is important to take your nausea medications as recommended for you (for example, regularly through the day, or at the first signs of nausea). When experiencing nausea, it can be helpful to do distracting mental activities to take your mind off the nausea (for example, crosswords, puzzles or reading emails). Relaxation exercises can also reduce nausea.

See "Looking after your mind and body" on page 16 for tips on reducing nausea.

Hot flushes / night sweats

Hot flushes and night sweats can be a side-effect of some cancers and cancer treatments. These can cause frequent night-wakings and poor sleep.

Sometimes these symptoms are unavoidable. Sometimes there are things that can trigger hot flushes (such as alcohol or spicy foods). It may be helpful to identify specific triggers for your hot flushes. Avoiding these triggers and doing things to help you manage changes in your body temperature may be useful for you.

Some suggestions for managing body temperature include:

- wearing cotton (to allow your skin to breath)
- wearing layers of night clothes (to quickly cool down or warm up) and having spare clothes within easy reach (if you need to change)
- having layers of sheets/blankets at night that can be easily adjusted to suit changes in body temperature
- using towels to help absorb perspiration
- adjusting your bedroom temperature to suit.

Keeping the following near your bed may help you to cool down:

- a cool drink
- a water spray
- a hand-held or electric fan
- an ice-pack or cooling pillow
- a small bucket of water and flannel to place against your face or body.

Discuss your symptoms with your health care team as there may be medication options that can help with your symptoms. They can also refer you to a specialist gynaecologist or menopause clinic if your symptoms are related to menopause.

Urinary changes (changes in how you wee)

Urinary changes may occur in some cancers and cancer treatments, or as a result of getting older. 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 lead to frequent night-time wakings and longer periods of being awake at night.

- Speak to a health professional about lifestyle changes and treatment options (for example, your GP, urologist, a urology or continence nurse, physiotherapist). Medication may be recommended in some cases.
- Consider when you drink fluids and how much fluid you drink. It is a good idea to avoid having additional large quantities of fluids after dinner time. Drinking caffeine and alcohol late at night will also make the problem worse.
- Empty your bladder 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.
- Wear an appropriate incontinence pad at night.
- Keep nightgown / slippers near your bed for easy trips to the bathroom.
- Wear easy to remove clothes (helpful if you need to go to the toilet in a hurry).

Bowel changes

Some cancers or cancer treatments may lead to changes in bowel function. Diarrhoea can result in frequent trips to the toilet through the night, which can be very disruptive to sleep. Constipation can also disrupt sleep by causing increased discomfort or pain.

Any changes in bowel function should be discussed with your medical team. Some issues can be managed through changing fluid and food intake and some may require medication.

Dry mouth

Keep water by your bedside within easy reach. Use a water spray or ice-cubes to wet your mouth. Speak to a health professional about products that can help with dry mouth (for example, mouth washes or artificial saliva).

Shortness of breath

Shortness of breath may be caused by medical factors, or stress and anxiety. Lifestyle factors may also affect shortness of breath, such as eating full meals just prior to bed. Speak with a health professional about your shortness of breath. Avoid things that contribute to your shortness of breath at night time. Try to engage in pursed-lip breathing (slow and deep in-breaths through the nose, and slow out-breaths through the mouth). Position your pillow to maximise comfort. Raising the head of your bed may help minimise stress and anxiety.

See "Looking after your mind and body" on page 16 for ideas that may be useful for you.

Steroid medications (dexamethasone, prednisolone or hydrocortisone)

Steroid medications may be used to prevent nausea or as part of some cancer treatments. They can have a stimulating effect and may make you more alert and awake. This is likely to make sleep more difficult. The best time to take your steroid medication is first thing in the morning (after some food) in order 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 unable to sleep. If sleep is a major problem when on steroids, you can discuss trying some sleep medications 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 you can do to manage pain.

- Talk to your doctor about the best pain medications to use, and the best time to take your medications to help with sleep.
- Consider ways to set-up your bed to minimise pain (for example, extra pillows or a comfortable mattress).
- Have pain medications (and drinking water) in easy reach of your bed in case you need to take an extra dose overnight.
- Discuss with a health professional other ways to help manage your pain, 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 that people with cancer may experience, including:

- pain
- nausea
- hot flushes
- dry mouth
- skin rashes or itch
- tingling or numbness in hands or feet
- or 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 help you 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 does not 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.

TIPS ON HOW TO COPE WITH UNPLEASANT SENSATIONS

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"Looking after your mind and body" on page 16 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:

6. LOOKING AFTER YOUR MIND AND BODY

Achieving a 'quiet mind'

This section includes CBT methods that will teach you how to focus your attention on one thing only, calming your mind. Practising these CBT skills will help you to slow down your thinking (quieten your mind) before bed. It is best to practice these every day to help manage stress and improve well-being. The more you practice relaxation, the better you will get at relaxing. You can also use these skills at night when you can't sleep.

An 'active mind' is when your mind is busy with lots of thoughts and/or worries. Your attention might jump from one worry to another, making it difficult to sleep. Your mind may focus on the past, or the future, rather than what is happening right now.

To help stop racing thoughts about the past or future, it can be helpful to practice focussing your attention on what is happening right here and now. The easiest thing to focus on 'right now' is your breath.

- Bring your attention to your breathing. Notice your chest rise and fall 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. Don't judge or get upset by this. Simply bring your attention back to your breath each time. Over time, this exercise helps you learn to control your attention better and slow down racing thoughts.
- It is ideal to do this exercise daily (for example, for 10 or 15 minutes) to gain the most benefit. However, even a few mindful breaths while 'on-the-go' may be helpful.

Some people find activities such as yoga, meditation, or mindfulness very helpful in achieving a quiet mind. There are many books, CDs, apps or audio-guides that might be useful for you.

Relaxation for your mind and body

Tension, stress, and anxiety are common feelings during and after cancer. These feelings can cause tight muscles or tension in the body. Signs of tension might include:

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

Everyone experiences tension differently. The problem with physical tension is that it sends 'stress signals' to the brain. This produces chemicals that cause muscles to tense even more. As we sleep better when we are relaxed, rather than tense, this vicious cycle often makes sleep even more difficult. Learning how to relax is a useful CBT approach for sleep.

Write down the signs of tension you experience here:

Become more aware of your tension on a daily basis. Every now and again, pause and notice the tension in your body. Deliberately relax those muscles, and slow down or deepen your breathing. Do this as often as you can during the day, especially during periods of stress. You can also check for tension when trying to sleep.

Deep breathing

Deep breathing is a very effective way to become more relaxed.

- Simply breathe in slowly and deeply, all the way to your belly. Then let your breath out using a slow and controlled manner. Some people like breathing in through their nose, and out through their mouth (using pursed lips, to help slow the breath out). Do whatever is most comfortable for you.
- You can practice this regularly (10-15 minutes each day) to help with general relaxation and well-being. You can also use it in bed while trying to fall asleep. Taking a few deep breaths may be enough to help you relax and remove tension from your body.

Note: Deep breathing may be uncomfortable for some people with cancer. If this is the case for you, try another method of relaxing instead (eg. progressive muscle relaxation).

Progressive muscle relaxation

- This relaxation 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, and work 'progressively' through your arms, body, legs and feet.
- Repeat this as many times as needed.

Useful resources for relaxation: There are a wide variety of relaxation tools and resources you can explore. For example, there are books, CDs, apps or websites that provide relaxing music or guided relaxation exercises. Try a few different ones until you find one that feels right for you. Some people use these when trying to fall asleep. Other people use them during the day time.

See "Additional treatments and resources for sleep" on page 22 for some suggestions.

How to manage your worries

When you are first diagnosed with cancer, and as you progress through different phases of treatment or beyond, it is natural to feel a range of difficult emotions. Common emotions include distress, fear, anxiety, loneliness, uncertainty, anger, sadness and worry. There is no right way to feel. Experiencing a range of different emotions is normal and everyone will cope differently. One of the problems for sleep is that worries and fears can feel 'bigger' at night time. Learning how to manage worries and fears is important in improving sleep.

Worry time

People often try to avoid thinking about stressful or worrying thoughts. These thoughts tend to come back however, especially when we are tired and can't distract ourselves (such as when trying to sleep). It may be more helpful to set aside about 30 minutes each day (at least 2 hours before bedtime) to focus on these worries. This CBT method is called 'Worry Time'.

During this worry time, try writing all your worries on a bit of paper.

Next, identify which worries are solvable problems (problems you can do something about). Hint, this may mean focussing on 'how' statements (for example, "How can I make this better"), rather than 'why' or 'what if' statements (such as "Why did this happen to me" or "What if things get worse").

- 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 tasks.
- 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 could help you complete or achieve each step.
- Try not to worry about 'solvable problems' in bed. Tell yourself: 'I have written this down and I will tackle it tomorrow'.

Identify which worries are unsolvable problems (things you cannot necessarily 'fix').

A very common thought for people with cancer is 'What if my cancer comes back?' This is an example of an unsolvable problem. It is natural to worry about prognosis, treatment, and the impact your diagnosis will have on your family, work and other aspects of your life. As frightening as these thoughts can be, they are simply thoughts that our 'active mind' creates. They may have no relation to what the future will actually bring.

Although it is understandable that you will have these thoughts from time to time, focusing on these worries can simply be unhelpful.

- Remind yourself that these worries are about the future. They are far from what is happening right here, right now.
- Focus on skills covered in the 'quiet mind' section.

See "Looking after your mind and body" on page 16 to focus on the skills in achieving a 'quiet mind'.

- Try the following activities:
  - Leaves on a stream - Imagine yourself sitting next to a stream with leaves floating on the surface. As worries go through your mind, imagine putting them on the leaves one at a time, and watch them float further and further away with the stream.
  - Thought bubble/cloud - Imagine your thoughts or worries are like bubbles or clouds coming into your vision, and floating by. See whether you can watch them come and go in front of you without trying to respond to or interact with them.

Seeking help for emotional concerns

It is a normal human experience to struggle with emotional concerns, especially during difficult and challenging times. In situations where your emotional health is interfering with sleep, it may be useful to seek help for these concerns in addition to tackling sleep problems using the CBT methods in this booklet. You may find it helpful to open up to friends or family, or look into support groups or community services for assistance. Cancer Council Victoria provides a wide range of supports and resources to people with cancer and their families.

Consider speaking to your GP, or the nursing, medical or allied health staff at your treating hospital. You could also consider seeing a social worker, counsellor, psychologist or psychiatrist, or discussing medication options with your GP or medical team. There are many ways to seek help, and people are often relieved and surprised to hear how normal their experiences are, and to know of the many support options available.

7. TRACKING YOUR SLEEP

Some people find it helpful to keep notes on their sleep each night, to see patterns in their sleep, and see changes or improvements over time. For example, you could keep a record of:

- The time you went to bed
- The time you woke up
- How many times you woke during the night
- How many hours of sleep you had
- How refreshed you feel when you wake, or the quality of your sleep (rate out of 5).

You could also make notes of other aspects of your sleep, or of 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 this booklet.
- There are useful smart-phone apps and fitness activity devices that help track your sleep. However, the accuracy of these devices is sometimes poor.

8. MEDICATIONS AND HERBAL REMEDIES FOR SLEEP

Medications for sleep

The CBT methods in this booklet are known to help sleep problems such as insomnia, and may help reduce the need for sleep medications. CBT is just as effective as medications in the short-term, but is more beneficial than medications in the longer term. As such, sleep medications may be helpful for short periods of sleep disturbance, or in combination with CBT while sleep problems start to get better. For some people however, ongoing medications for sleep may also be a suitable option, especially if unable to engage in the CBT methods mentioned in this booklet.

There are many different types of medications that are used to help with sleep (including melatonin, anti-depressants, anti-anxiety medications such as valium, and a range of other medications). It is important to be aware that all medications have side-effects. Some can also become addictive or lose their effect if taken for more than the recommended time. Some medications may be harmful if stopped suddenly. It is important that you seek the advice and input from your GP or medical treating team.

Herbal remedies for sleep

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 for sleep problems, the research on this is unfortunately quite limited. Some herbal remedies can 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.

9. STOPPING SLEEP PROBLEMS FROM COMING BACK

Don't worry too much if at some point in the future your sleep problems return. This is a common experience, especially during times of stress or change. Even the best sleepers have a bad night's sleep from time to time. The following steps might help you know when you need to improve your sleep, and what you can do.

It can be helpful to know your early warning signs. These are signs that tell you that your sleep is getting worse, so you can do something sooner to improve your sleep. Early warning signs might include starting to wake a lot at night, or starting to feel stressed or worried about going to bed.

The following questions might help you put a plan into place to keep your sleep on track:

- What early warning signs will tell you your sleep is getting worse?
- Are there times or situations in the future you know will impact your sleep?
- What helped you improve your sleep in the past? Can you do these things again, to stop your 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 booklet as often as you need. Don't be afraid to seek additional help or assistance from others too.

10. ADDITIONAL TREATMENTS AND RESOURCES FOR SLEEP

This booklet covers some of the most important Cognitive Behavioural Therapy (CBT) methods for sleep. We hope many people will find it useful in improving their sleep.

However, some people will find it more helpful to do CBT for their sleep problems with a trained professional. A trained professional may help you tailor CBT methods to your situation, and may help you with CBT ideas not included in this booklet.

Some psychologists are trained to help people improve their sleep using CBT approaches. Other practitioners may also be able to help you with CBT methods for sleep (for example, some GPs, occupational therapists, social workers, or nurses). There are also specialist sleep clinics to help with insomnia and other sleep problems.

- Ask about relevant CBT services at your treating hospital.
- Speak with your GP about options in the community. GPs can refer you to an accredited health professional (such as a psychologist), and you may be eligible for a Medicare rebate to help cover the cost.
- Consider going to a specialist sleep clinic for help. The Sleep Health Foundation website provides a "find a sleep service" feature that can help you locate an appropriate service near you.

Websites to find out more about sleep.

The following websites provide further information on sleep:

- Sleep Health Foundation
  www.sleephealthfoundation.org.au
- National Sleep Foundation (USA)
  www.sleepfoundation.org
- The Better Health Channel
  www.betterhealth.vic.gov.au/health/conditionsandtreatments/sleep

Other useful resources

Cancer Council Australia (and in each State and Territory) provide 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.

INFORMATION FOR HEALTH PROFESSIONALS

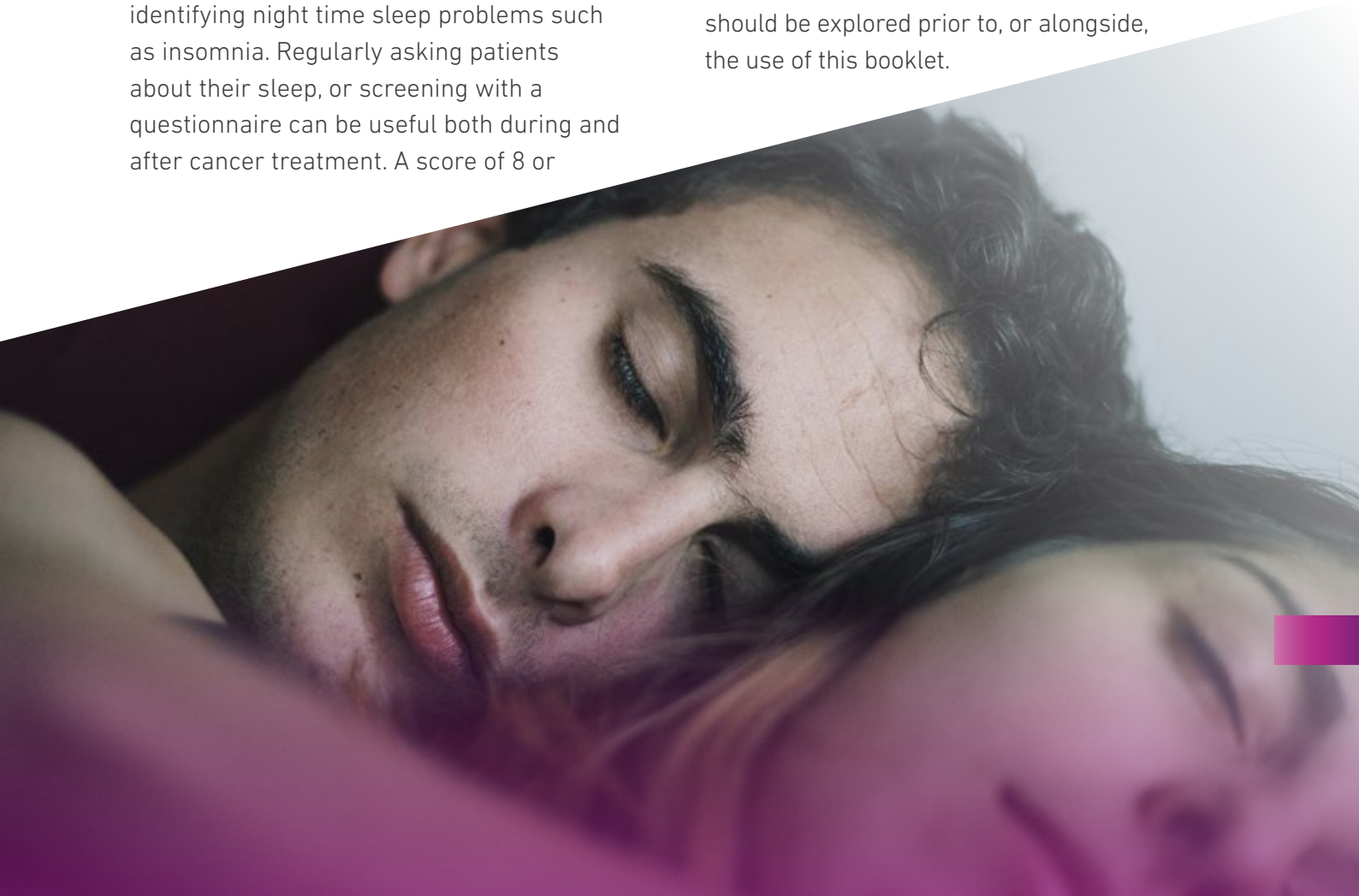
1. HELPING CANCER PATIENTS WITH SLEEP PROBLEMS

This booklet is a self-management guide to cognitive behavioural approaches to treating insomnia and other night-time sleep disturbances in people with cancer. Patients can use this booklet 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 night time sleep problems such as insomnia. Regularly asking patients 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[3] (© Morin, C.M. 1993, 1996, 2000, 2006) is a useful indicator of sleep problems that may be helped by use of this booklet.

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. 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 booklet.



Use of this booklet

Health professionals can assist patients in the use of this booklet in the following ways:

- Determining if this booklet is relevant for your patient (see page 1)
- Helping identify the most useful sections of this booklet for your patient
- Offering periodic review appointments (for example, 3 and 6 weeks after the person starts using this booklet), to review progress, troubleshoot barriers to change, and provide encouragement and guidance.
- Assessing lifestyle habits and treating cancer-related problems that may be causing or contributing to night-time sleep difficulties. Common issues are overviewed in Sections 4 and 5 of this booklet, and may prompt review and discussion with your patients.
- Providing advice and guidance on the use of pharmacological interventions for insomnia or other sleep problems. Please refer to Section 8 of this booklet (page 20) as well as the practice guidelines published on the American Academy of Sleep Medicine's website https://aasm.org/clinical-resources/practice-standards/practice-guidelines/

For people with chronic insomnia, sleep hygiene interventions alone (such as in "A healthy lifestyle for sleep" on page 10) may not significantly improve symptoms. Helping patients apply skills from multiple sections in this booklet may lead to better outcomes.

Referral to a specialist in CBT for sleep (such as a psychologist) should be considered if sleep problems do not improve after use of this booklet.

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NOTES

NOTES

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Prof Michael Jefford
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Ms Amanda Piper
Manager, Australian Cancer Survivorship Centre, a Richard Pratt legacy

Georgina Akers
Senior Project Officer, Cancer Strategy and Development, Department of Health and Human Services, Victoria

Dr Bei Bei
Monash Institute of Cognitive and Clinical Neurosciences, Monash University

Dr Joshua Wiley
Monash Institute of Cognitive and Clinical Neurosciences, Monash University

Helena Bean
Monash Institute of Cognitive and Clinical Neurosciences, Monash University

Prof Bruce Mann
Director Breast Cancer Services, Peter Mac & Royal Women's Hospital

Prof John Seymour
Director of Cancer Medicine, Peter Mac

Prof David Ball
Director Lung Service, Peter Mac

Prof Orla McNally
Director Gynae-Oncology Service, VCCC

A/Prof Declan Murphy
Director Genitourinary Oncology, Peter Mac

Dr Greg Wheeler
Chair Paediatric & Late Effects Service, Peter Mac

A/Prof Lou Irving
Director of Respiratory & Sleep Medicine, Royal Melbourne Hospital

Prof Martha Hickey
Director Women's Gynaecology Research Centre, Royal Women's Hospital

Dr Dennis Carney
Haematologist, Peter Mac

A/Prof Linda Mileshkin
Deputy Director of Medical Oncology, Peter Mac

A/Prof Anne Hamilton
Consultant Medical Oncologist, Peter Mac

Dr Nikki Plumridge
Radiation Oncologist, Peter Mac

Sarah Pratt
Breast Nurse Consultant, Peter Mac

Lisa Sheeran
Breast Nurse Consultant, Peter Mac

Monique Baldocchino
Breast Care Nurse, Royal Women's Hospital

Claire Noonan
Breast Care Nurse, Royal Woman's Hospital

Kerry Shanahan
Breast Nurse Consultant, Royal Melbourne Hospital

Susan Thomas
Breast Nurse Consultant, Royal Melbourne Hospital

Nicole Kinnane
Gynae-Oncology Nurse Consultant, Peter Mac

Danielle Carpenter
Gynae-Oncology Nurse Consultant, Peter Mac

Yvonne Panek-Hudson
Haematology Nurse Consultant, Peter Mac

Odette Buelens
Haematology Nurse Consultant, Peter Mac

Trish Joyce
Haematology Nurse Consultant, Peter Mac

Tracey Dryden
Haematology Nurse Consultant, Peter Mac

Nicole O'Leary
Haematology Nurse Consultant, Peter Mac

Lea Thornton
Genitourinary Nurse Consultant, Peter Mac

Marc Diocera
Genitourinary Nurse Consultant, Peter Mac

Marianne Heppell
Genitourinary Nurse Consultant, Peter Mac

Mary Duffy
Lung Nurse Consultant, Peter Mac

Sarah McLean
Lung Nurse Consultant, Peter Mac

Natalie Goroncy
Late Effects Nurse Consultant, Peter Mac

Tanya McKenzie
Health Literacy Manager, Peter Mac

Peter MacCallum Cancer Centre

305 Grattan Street
Melbourne Victoria
3000 Australia

Locked Bag 1 A'Beckett Street
Victoria 8006 Australia

Phone: 03 8559 5000
Fax: 03 8559 7379
Referrals (fax): 03 8559 7371

Peter Mac at Bendigo Radiotherapy Centre

Bendigo Hospital
100 Barnard Street
Bendigo, Victoria 3550
Phone: 03 5454 9234

Peter Mac at Box Hill

Epworth Eastern Medical Centre
1 Arnold Street
Box Hill, Victoria 3128
Phone: 03 9895 7539

Peter Mac at Monash Cancer Centre

Moorabbin Hospital
825-865 Centre Road
East Bentleigh, Victoria 3165
Phone: 03 9928 8901

Peter Mac at Sunshine Hospital Radiation Therapy Centre

176 Furlong Road
St Albans, Victoria 3021
Phone: 03 8395 9999

Peter MacCallum Cancer Foundation

Phone: 03 8559 7777 (donation enquiries)
Freecall: 1800 111 440 to donate
Email: foundation@petermac.org

www.petermac.org

CAN-SLEEP: MAKING NIGHT-TIME SLEEP PROBLEMS GO AWAY

A guide for people with cancer

For more information, please contact the Can-Sleep team:

- **Phone:** 03 8559 5265
- **Email:** CanSleep@petermac.org