



Australian Government



Carer Skills 6:

Sleep



How long will it take?
20 to 40 minutes



Learning outcomes

In doing this module you will:

- ✓ learn more about sleep and its importance to your health and wellbeing
- ✓ learn if you are getting enough sleep and the consequences of inadequate sleep
- ✓ understand why you don't get enough sleep and what you can do about it
- ✓ develop strategies to manage your day after poor or no sleep
- ✓ create your care team
- ✓ develop your plan to improve your sleep
- ✓ commit to putting your plan into action.



Your wellbeing is important to us.

If you find talking about your experience as a carer upsetting, you may want to talk to someone.

Lifeline 13 11 14 and Beyond Blue 1300 22 4636 are two services that are both available 24 hours a day, 7 days a week if you need support.

Introduction

We spend about one-third of our life sleeping, yet the importance of sleep to our health and wellbeing is often poorly understood and overlooked.

What is sleep?

Sleep is an active body state, which means that while you sleep our brains and bodies are busy with important functions to maintain our health and wellbeing. While we don't know all of the functions that sleep serves, we know it seems to have an important role in memory storage and cell repair around our bodies.

In a nutshell, you need sleep to repair, recharge and recover for the next day.

There are different types of sleep that cycle through the night. We start the night with mostly 'slow wave sleep' which is the deepest stage. Some cycles are lighter than others and waking briefly a few times a night is normal. Dreams happen mostly in a stage called rapid eye movement (REM) sleep.

By the time we reach adulthood, our sleep is mostly achieved in one sleep opportunity, overnight. Wakings as an adult are normal and are usually so brief we don't even know they have happened. The important thing about night-time waking is that you can get back to sleep in a reasonable time without stress.



As we get older, night wakings are even more common and while still normal can be caused by:

- certain medications
- illness
- pain
- living arrangements, for example your partner might be a restless sleeper or snore loudly
- loneliness
- stress.

Introduction



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Understanding normal sleep across the lifespan

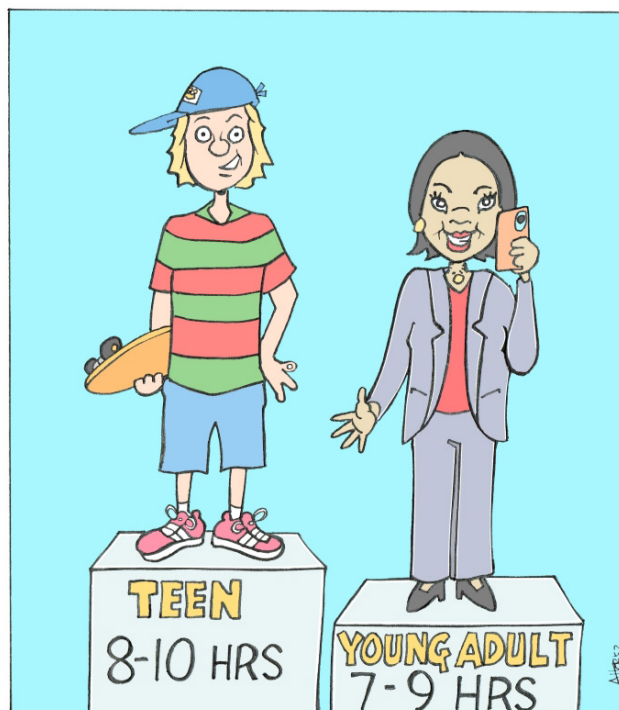
Sleep needs vary from person to person and change with age.

One way to see how much sleep you need is to go to bed at a consistent time every night and sleep until you wake without an alarm clock feeling refreshed.

How much sleep do I need?

Below are some healthy sleep ranges which have been proposed by the American National Sleep Foundation:

- newborns (0-3 months) need between 14 to 17 hours sleep
- infants (4 to 11 months) need between 12 to 15 hours sleep
- toddlers (1 to 2 years) need between 11 to 14 hours sleep
- pre-schoolers (3 to 5 years) need between 10 to 13 hours sleep
- school age children (6 to 13 years) need between 9 to 11 hours sleep
- teenagers (14 to 17 years) need between 8 to 10 hours sleep
- young adults (18 to 25 years) need between 7 and 9 hours sleep
- adults (26 to 64 years) need between 7 and 9 hours sleep
- older adults (65+ years) need between 7 and 8 hours sleep.



I used to pay more attention to this when they were little, but it's helpful to know that the kids are needing less sleep now that they are getting bigger. Looking at this was a little bit of a shock for me as I'm definitely not getting 7 hours ... might explain why I feel so tired all the time.

Megan (44), mother of two, working full-time and carer to her sister, Liz (43), who has Down Syndrome.

How do I know if I'm getting enough sleep?



Getting enough sleep is more than just the total hours you spend in bed. It's also about the quality of sleep. Good quality sleep can mean different things to different people but in general, good quality sleep is where you:

- regularly fall asleep in less than 30 minutes
- don't wake too early
- don't have trouble falling:
 - asleep
 - back to sleep when you wake up during the night.

Sometimes whether we've had enough sleep is not obvious, so ask yourself the following questions to get an idea of how well you sleep from night to night.

- Do you wake up feeling refreshed?
- Do you feel like your sleep was restless (lots of wakings)?
- Could you fall asleep just about anywhere at anytime?
- Are you often tired throughout the day, no matter the time of day?
- Do you feel irritable and stressed throughout the day?
- Do you have trouble concentrating and remembering?
- Do you struggle to think critically, problem solve and be creative?
- Are you using caffeine to get through the day?
- Do you get drowsy while reading, watching TV or driving?

If you answered no to the first question and/or yes to any of the other questions, you could benefit from doing this module.



I know I'm not getting enough sleep, instead I'm usually up until late worrying about Daniel, and whether he will come home safe.

Cheryl (56), carer and parent to her son, Daniel (33), who abuses substances and her daughter, Lily (29), who has generalised anxiety disorder.

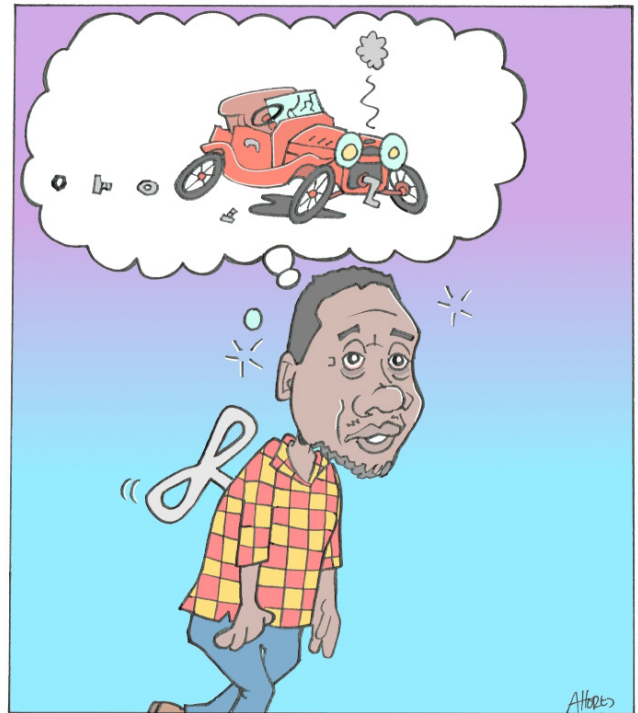
Consequences of inadequate sleep



We all know feeling sleepy or tired is a sign of inadequate sleep, but that's just one of many symptoms. A lack of sleep, both in the short and long term, can impact many aspects of our health and wellbeing.

Some of the more common consequences of inadequate sleep include:

- how you think:
 - increased stress and worry – small things become 'big'
 - poor decision-making
 - impaired problem-solving ability
 - poor sense of judgement
- how you feel:
 - moody
 - irritable
 - emotional, sad, vulnerable
 - angry or short tempered
- impacts to your health:
 - more susceptible to illnesses like colds or other viral diseases
 - changes to hunger and appetite hormones – crave foods higher in sugar or might be hungry, or not hungry, at unusual times
 - body processes food differently which can make you more susceptible to weight gain and in the longer term, health conditions such as type 2 diabetes
 - poor control or management of pre-existing medical conditions



- how you perform:
 - reactions are slower
 - coordination can be impacted – you might feel clumsy
 - more likely to make mistakes or have accidents
 - take more risks

Did you know 17 hours without sleep impairs your driving in the same way as having a blood alcohol level of 0.05 per cent?

Consequences of inadequate sleep



While inadequate sleep may be unavoidable at times for carers, recognising the impact is important. It is helpful to know how your mental, emotional and physical functioning are affected for two reasons so:

- that where you have the choice, you can change or modify your behaviour or activities
- you can be kind to yourself in terms of how you do things and interact with people.

When you are sleep deprived you may not be aware of how impaired or sleepy you actually are. Keeping track of your sleep can help you anticipate how you might be impacted.

Sleep deprivation and fatigue

It is not unusual for carers to feel sleep deprived or fatigued, especially where high level or time demanding care is provided. Many carers do things which need complex thinking multiple times during the day and night, for example:

- manage/dispose medications
- perform medical procedures such as wound management, bowel care or implementing medical emergency action plans
- operate machinery
- drive.

If you feel that you are sleep deprived or fatigued and you are concerned about your ability to provide care to the standard that is required:

- speak to your GP about the impact of your caring responsibilities on your:
 - health and wellbeing
 - ability to provide sustained ongoing care
 - duty of care responsibilities



- create a care team to support you and the person you care for.
- if the person you care for is an NDIS client, talk to your planner, ECEI or support coordinator about the need for additional support because of the impact of your sleep deprivation and fatigue on your:
 - health and wellbeing
 - ability to provide sustained ongoing care
 - duty of care responsibilities.

Consequences of inadequate sleep



Further information

A resource about duty of care responsibilities is included in the Additional resources at the end of the module.



I used to be so calm and would sleep like a log – now I can't help but feel on edge all night worrying about Jane and wanting to be sure that I can get up to help Henry (10 month old son) as Jane needs to rest now more than ever. I know that I'm not pleasant to be around but I just don't know how to fit it.

Ian (35), carer to his wife, Jane (28), who has a diagnosis of breast cancer

Why don't I get enough sleep?



Disturbed sleep is common among carers. There are many reasons why carers don't get enough sleep. The list below has been developed to help you work out what disturbs your sleep:

- you may have a medical condition or take medication which affects your sleep
- you may have an undiagnosed sleep disorder
- the person you care for may disturb your sleep, for example:
 - they don't sleep well because they have poor sleep habits, worry or stress, have nightmares etc
 - you provide 24/7 care
 - you need to be alert to alarms or the needs of the person you care for overnight
- you may have poor sleep habits
- you may worry or stress about:
 - the health and wellbeing of the person you care for
 - the future of the person you care for
 - financial concerns
 - managing caring and working or studying
 - managing caring and family responsibilities
 - having adequate support around you and the person you care for
 - what will happen to the person you care for if you are unable to provide care
- you may go to bed after or get up earlier than the person you care for so you can:
 - have some 'me' time
 - get jobs done
 - provide morning care
- you feel exhausted because you are on the go every day.



Why don't I get enough sleep?



Regularly getting good quality sleep can be difficult when:

- the person you care for and family and friends may not understand that sleep is as important to your health and wellbeing as diet and exercise
- family and friends may not understand that you need support
- the person you care for doesn't want outside help
- the demands of other family members make it difficult for you to prioritise your sleep.



Ever since the accident 39 years ago, I gave up work to take care of my son, Con. As Con got older, caring for him got harder. When my health problems started, it made it even harder to care for him. Now that I have daytime support workers some of the pressure is off, as they can help me with caring for him. But, unfortunately, I still wake up in pain throughout the night and so never feel rested.

Julia (85), carer to her son Con (55), who is non-verbal, has an intellectual disability and needs assistance with all activities of daily living

What can I do about my sleep disruption?



It may take a little time to work out why you're not sleeping as there may be more than one reason. However, the time you invest will be worth it to have better sleep.

The step-by-step process below has been developed to help you do this.

Step 1 – ruling out common medical causes

Some common diseases/conditions and medications can disturb your sleep such as:

- physical conditions
- neurological disorders, which are diseases/conditions of the brain, spine and the nerves that connect them
- mental health disorders
- medications.

A **resource** has been developed to help you work out if there is a medical cause affecting the quality or quantity of your sleep. If you think there might be a medical cause you should make an appointment with your GP as soon as possible.

Step 2 – you might have an undiagnosed sleep disorder

The cause of your poor sleep could be a sleep disorder. Some of the more common sleep disorders are:

- insomnia – difficulty getting to or staying asleep for at least three nights a week for three months or more – 20 per cent of Australians suffer from episodic or chronic insomnia



- sleep apnoea – 8 per cent of Australians have been diagnosed with sleep apnoea and it is estimated that 80 per cent of people with sleep apnoea remain undiagnosed – symptoms include:
 - loud or frequent snoring
 - pauses in breathing, which may be noticed by other people
 - choking or gasping sounds
 - daytime sleepiness or fatigue
 - unrefreshing sleep
- restless leg syndrome – unpleasant or uncomfortable sensations in your legs and an irresistible urge to move them – 18 per cent of Australians suffer from this condition.

What can I do about my sleep disruption?



If you think you might have a sleep disorder, you should make an appointment with your GP as soon as possible. Many sleep disorders can be diagnosed through a sleep study undertaken in the home. More complex sleep health conditions need a diagnostic study at a sleep laboratory.

Step 3 – is the person you care for disturbing your sleep?

There is a strong relationship between the sleep of the carer and the sleep of the person being cared for. A **resource** has been developed to help you determine if the person you care for is disturbing your sleep and it includes some ideas to help you deal with the situation.

Step 4 – are your caring responsibilities disturbing your sleep?

Many carers:

- worry and stress about a range of things – see resource 'Worry time'
- go to bed after and get up earlier than the person they care for.

If you are worried and stressed you should make an appointment with your GP as soon as possible to discuss treatment options.

If you go to bed after and get up earlier than the person you care for, you could create a care team to support you and the person you care for.

Step 5 – sleep diary

Keeping a sleep diary for one or two weeks to track your sleep patterns and habits can be useful:

- in helping you:
 - gain a better understanding of how the things you do through the day affect your sleep
 - confirm whether or not you are getting enough sleep
- in helping your GP diagnose and treat your symptoms
- as evidence to obtain services, such as replacement care or help with other caring or household tasks.

In the diary you will record information such as:

- the time you went to bed and got up
- how easily you fell asleep
- the number, and length, of times you woke during the night

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How can I improve my sleep?



There are many things you can do to improve your sleep.

Making sleep a priority

The nature of being a carer makes it challenging to prioritise sleep. A **resource** has been developed to help you find room for more sleep.

Good sleep habits for carers

Making simple changes to your daytime routine and bedtime habits may improve your sleep. A **resource** has been developed to help carers create good sleep habits. The resource includes information about:

- creating a regular sleep pattern
- spending the right amount of time in bed
- being comfortable in your sleeping environment
- winding down and relaxing before going to bed
- knowing the effects of alcohol, caffeine and cigarettes
- not lying awake watching the clock
- carefully considering the use of sleeping pills
- when to seek professional help
- re-establishing routine after periods of major disruption.

You might find it easier to make incremental changes. Changing one habit at a time can be an effective way to improve your sleep. And remember it takes time to change habits.

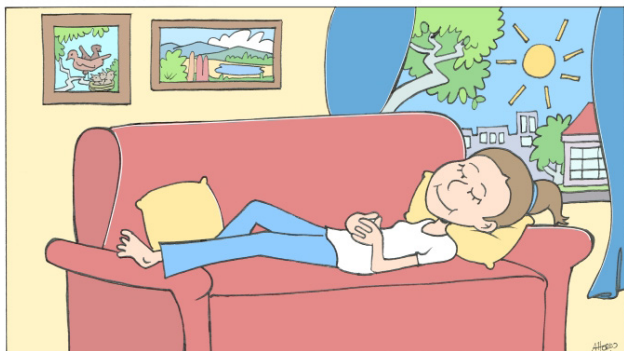


Sleep in young carers

The sleep needs of young people differ from adults. A **resource** has been developed to help young carers understand how:

- their body clock affects their sleep
- to manage their sleep need.

How can I improve my sleep?



All the ways to get sleep – sleep strategies

A **resource** has been developed to help you find ways you can meet your sleep needs across a 24-hour period. Suggestions include:

- daytime sleep
- naps
- split sleep – where you plan to get your sleep in multiple blocks
- broken sleep – where your waking between sleeps is unplanned
- sharing the night 'shifts'
- where to sleep.



Replacement care

Using replacement care is another way for carers to 'catch-up' on sleep. A **resource** has been developed which includes information about:

- when to use replacement care
- location of the replacement care
- handing over care
- how to manage the day after the replacement care
- your own sleep health
- developing a 'to do' list for the replacement carer.

How can I improve my sleep?



Cognitive behaviour therapy - insomnia programs

Cognitive behaviour therapy for insomnia (CBT-I) is an effective treatment if you have trouble falling asleep, staying asleep or getting quality sleep. It is effective because it addresses the underlying causes of insomnia by identifying and changing the thoughts and behaviours that affect the person's sleep. Common techniques used in CBT-I include:

- stimulus control – reduces anxiety about going to bed by using a set of instructions designed to reassociate the bed/bedroom with sleepiness instead of stimulation
- sleep habits – environmental and lifestyle factors that may affect sleep
- sleep restriction – reduces the amount of time spent in bed to achieve higher quality sleep over a shorter period
- relaxation training – can include progressive muscle relaxation techniques, deep breathing exercises, meditation and visualisation to help people relax throughout the day and particularly close to bedtime
- cognitive therapy – deals with dysfunctional thoughts and attitudes about sleep.

Online CBT-I has been found to be an effective treatment for insomnia. CBT-i Coach is a free app developed by Sanford for the US Department of Veterans Affairs. Please note that the app contains some veteran specific advice.



Mum tries her best to take care of us, but when her sleep gets disrupted her mental health suffers. I usually find that when mum gets unwell, my sleep suffers as I'm so worried about her and her safety. Inevitably, its only when she's feeling better or ends up in hospital that my body starts to relax again as I know that she's safe ... at those times I can start to play catch up and get onto a better sleep routine again.

Joe (17), carer to his mother, Michelle (36) with Bipolar Disorder and Fibromyalgia

What do I need to follow-up?

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Waking up is hard to do – Sleep inertia



Do you find that when you first wake up, you feel a bit 'fuzzy'? Or you might be slightly disoriented, uncoordinated, forgetful? Feeling like you haven't properly woken up is normal and is called 'sleep inertia'.

We know that during those first 10 to 15 minutes (sometimes longer) immediately after we wake, we are not performing at our best. For most of us, sleep inertia is not an issue. We usually have time to slowly wake up and can delay any urgent or crucial tasks until we are feeling fully alert. However, many carers regularly wake up or are woken in the middle of sleep and have to act quickly, for example when you:

- wake to an alarm to do a planned task, such as administer regular medication during the night
- are woken unexpectedly, for example by a noise or perhaps a sensor alarm indicating that you need to urgently attend to the person you care for.

Can you eliminate sleep inertia?

There are no evidence-based ways to speed up or eliminate sleep inertia. Some people find the adrenaline rush they get from being suddenly woken for an emergency helps. Others find a cold shower, or splashing cold water on their face helps them wake up more quickly.

As a carer, the best thing you can do is to be aware that when you wake, where you can, adjust or modify what you have to do until you've had time to properly wake up. Below are some tips and information that may help you be more aware of sleep inertia and what you can do about it:



- be aware that during the first 10 to 15 minutes you may not be at your best in decision-making, response times, communication, problem solving and coordination
- give yourself more time to do things
- be kind to yourself if you are not as coordinated or fast or as good at remembering
- explain the situation to the person you care for.

Waking up is hard to do – Sleep inertia



If you can, delay activities that require complex thinking such as measuring medications. If you don't have that choice, make the task as simple as possible. For example:

- is it possible to prepare anything, such as equipment, in advance when you're feeling alert?
- can you write instructions, medication dosages, other observations down (even if very simple)?
- know that waking in the middle of the night, rather than the day, or being woken by a noise or alarm, rather than naturally, can make sleep inertia worse – where possible try to account for your poorer performance during these times.



I've never been much of a morning person, but Sue is – so I'm planning to start getting some things set up the night before – like soaking oats overnight and setting the table for breakfast – this way the hard part is done and I can take it easier in the morning.

James (70) lives in a rural area and is carer to his wife, Sue (68), who experienced a stroke this year

What do I need to follow-up?

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How to manage your day after poor or no sleep

Most carers have nights of poor quality or frequently interrupted sleep. For many carers this is a nightly event which isn't within their control.

Where inadequate sleep is unavoidable, it is important to know the safety risks of some daily activities and tasks. For example, if you have no sleep at all one night, your performance as the night progresses will be equivalent to someone who has a blood alcohol reading of more than 0.05, which is the legal limit for driving in Australia. While some sleep is better than none, your ability to do some activities is affected even when you get as much as six hours of overnight sleep.

While you may not be able to change your sleep circumstances, paying attention to how much sleep you've had will help you work out your risk. You can then take action the next day to help you cope, be safe or just feel better. Below are some tips which might help when you haven't had enough sleep.

Know how sleep deprivation affects you

It is important to note that when you are sleep deprived you may not be aware how impaired or sleepy you actually are.

Sleep loss affects people in different ways, and some people cope better than others. Take note of how sleep deprivation affects you so you can develop strategies to deal with it. For example, get to know your sleep/wake cycle:



- if you are a morning person, do the things that need more energy in the morning and the things that need less energy in the afternoon
- if you are more tired in the afternoon, try to schedule a rest or nap when you are more naturally tired
- find out when you are more alert and schedule the things that need more accuracy for then.

How to manage your day after poor or no sleep



Decision-making and memory

Be aware that your decision-making may be slower and your memory may not be as good. Where possible, avoid making big decisions or doing activities which rely on memory when you are sleep deprived.

Give yourself more time to get things done

If you can, give yourself more time to get things done, especially things where you need to be precise, for example medication management.

Non-urgent activities

Where you have the choice, put off non-urgent activities until you are feeling less tired or have had more sleep, particularly if safety is a factor, for example driving.

Get some sunshine

Get about 30 minutes of sunshine as soon as you can after you get up. Morning light will help energise you, improve your mood and reset your body clock.

Caffeine

Caffeine (found in coffee, tea, energy drinks, colas etc) is very effective at improving your alertness and performance for a few hours. For example, if you need to drive somewhere, a cup of coffee 20 to 30 minutes before the drive will give the caffeine time to 'kick-in' and help a little. Remember it's not a 'cure' for not enough sleep!

The Sleep Health Foundation has a factsheet about caffeine and sleep. A link to the factsheet is included in the Additional resources at the end of the module.

Feeling irritable, sad, angry or like it is all 'too hard'

All these emotions can be stronger when you haven't had enough sleep. Be kind to yourself and understand that when you are feeling like this your interactions with people – including the person you care for – may be strained or feel overwhelming.

Food cravings

You might be craving foods that are less healthy. This is normal, but foods that are particularly high in sugar can make you feel worse.

Naps

Take a nap. It doesn't matter for how long or where, as even short naps can improve how you feel and perform.

How to manage your day after poor or no sleep



Celebrate how much sleep you had rather than dwelling on how little sleep you had

Dwelling on how little sleep you've had saps your energy and leads to anxiety about how you are going to get through the day. Make a point of celebrating how much sleep or rest you had and be kind to yourself.

Get support if you can

If you can, get support with your caring or other tasks.

How will I manage my day after poor or no sleep? What will I avoid doing? What will I do differently?



After a big day with Ivy I'm exhausted. Then I want some time with Rob and some 'me' time. I know this means that I get less sleep overnight, and so often I end up laying in bed frustrated with myself that I should have gone to bed earlier. But, I've recently started this new thing ... I just simply lay down and celebrate the rest my body parts are getting ... how my ears don't need to listen to anyone talking, my hands don't need to help anyone, and my eyes and eyelids are able to close and rest. Before I know it I'm slowly drifting off to sleep.

Joanna (57) started caring for her friend, Ivy (79), who has heart disease, breast cancer and suspected cognitive impairment. Joanne lives with her husband, Rob (66)

What do I need to follow-up?

Creating your care team



Caring shouldn't be a one-person show. Creating a care team for you and the person you care for will benefit you both. It will also be a rewarding experience for all members of your team.

Often people don't offer support because:

- from the outside, it looks like you've got everything under control
- they don't know how to help
- they may be scared of doing a bad job.

And carers often don't ask for, or accept, help because they:

- don't want to be a burden on others
- feel as if they should have everything under control.

If this is you, be kind to yourself and understand people genuinely want to help – they just need to be asked or to have their offer accepted.

Even if family and friends aren't able to share overnight, or partial overnight, care to give you some 'protected' sleep, they may be able to pick up some non-caring tasks to ease your mental and physical load.

The first step is to develop a 'job list' of tasks and activities which other people can do to help, including providing care, so you can catch up on sleep. Make sure you keep the list up to date.

Use the template below to build your care team. You might be surprised at how much potential support there is around you and the person you care for.

Resource – How family and friends can help



It's a work in progress, but I've made a list of things that dad needs help with and have tried to organise more people to help.

I've built an online calendar for us all to use so we can see when dad needs help. Being an online calendar, everyone can see where they can help and, most importantly, dad knows who and what to expect every day.

I've also set up a transport service to help get dad out and about, and "Meals on Wheels" to deliver meals to his home.

I'm hoping that with all of this set up dad might be able to continue living independently, and I get some time back to get on with my life – fingers crossed!

Renee (22), carer to her father (48) with schizophrenia

Creating your care team



Family members

Family members can be a great support. Think about which members of your extended family could help. If they can't provide alternate care while you have uninterrupted sleep perhaps you could ask them to do a specific task on your job list. For example:

- spending time with the person you care for
- taking the person you care for on an outing while you have a nap or some time to yourself
- doing or collecting your grocery shopping, paying bills or helping out with other household and gardening tasks.

Even family members who live a long way away can contribute, for example they can give you some more time in your day by making medical appointments, regularly contacting your loved one (via telephone or video conferencing), paying bills electronically etc. List your family members who you will ask for support along with a task or activity.

Family member	Task/activity	Frequency

Creating your care team



Friends

Your friends and the friends of the person you care for may be able to help. You could ask a friend to do a task and see how the request is received. List the friends that you can approach along with a suggested task or activity.

Friend	Task/activity	Frequency

Neighbours

Neighbours can be a good source of support. Perhaps you can do something for a neighbour in return for some help with caring. List the neighbours you think can help along with a suggested task or activity for each person.

Neighbour	Task/activity	Frequency

Creating your care team



Other options

Other carers and peer support groups can be a great source of support because they are in a similar situation to you. Depending on the circumstances, you could swap care or do odd jobs for each other. List the other carers you know who might be in a position to help.

Church, social groups and clubs are another potential source of support. Think about the various groups of people that you and the person you care for are involved with who might be able to help and list them below.

Person/organisation	Task/activity	Frequency

Creating your care team



Paid in-home and out-of-home care

The following types of respite services are available:

- in-home respite
- centre-based respite.

The costs of these services will depend on your circumstances and those of the person you care for.

Depending on your circumstances and those of the person you care for, you could be eligible for:

- transport – taking the person you care for to and from appointments or on social outings
- domestic support – housework, personal care, gardening, odd jobs or repairs
- food services – shopping, food preparation or providing pre-cooked meals.

Once you have worked out which options apply to your circumstances, list them below

Person/organisation	Task/activity	Frequency

Building your plan to improve your sleep

You now understand how important sleep is to your health and wellbeing. Use the steps below to develop your plan to improve your sleep.

Step 1 – Get to the bottom of why you're not getting enough sleep.

For some people there may be only one reason why they're not getting enough sleep while for others it may be a number of factors.

Make sure you keep your GP informed about your sleep deprivation and what you are doing about it.

Step 2 – If necessary, get to the bottom of why the person you care for isn't getting enough sleep.

If your sleep is being disturbed by the person you care for, there may be things you can do to improve their sleep which, in turn, will improve your sleep.

Step 3 – Implement your strategies:

- to improve your sleep
- if necessary, to improve the sleep of the person you care for
- to manage your day after poor, or no, sleep.

Remember that change takes time. Be kind to yourself. It may take a little while to get to the bottom of your, or the person you care for's, sleep disturbance.



Step 4 – Put together your care team.

Talk to the family, friends, neighbours and others you identified as having capacity to support you and the person you care for.

You may want to get some tips from the Effective communication techniques module before you do this. A **resource** has been developed about how family and friends can help.

Remember, if they can't help with overnight care they might be able to help with replacement care during the day or other household or caring tasks.

Building your plan to improve your sleep



Step 5 – Arrange the paid in-home and out-of-home care you have identified as part of your care team.

These services can sometimes have waiting lists so it is best to book early.

Step 6 – Put together a care plan, including a daily activity sheet for the person you care for.

A **template** is included in the resources. If possible, do this with the person you care for.

Step 7 – Prepare the person you care for.

If possible, involve the person you care for at each stage and talk about the arrangements together. Try to be calm and cheerful. Be understanding if they are anxious or reluctant.

It may be difficult for the person you care for to adjust to receiving care from someone they don't know. Give lots of reassurance and encouragement. Explain that:

- you aren't trying to get away from them
- you're trying to improve your health and wellbeing so that your ability to care for them is not impaired
- improving your sleep will provide a better foundation for both of you
- you've put together a care plan which includes their routines, medications etc.

Involve other family members if you can.

When using replacement care make sure you keep the person you care for informed about who will be caring for them.

Review your plan

Regularly review your plan because it might need some tweaking to get it right. If you are using replacement care, involve the person you care for in the review and deal with any problems together. You might find it easier if you gradually introduce new people through shadow shifts.

Remember that other people do things differently to you. This doesn't mean their way is wrong, it may be good for the person you care for to experience different ways of caring.

If the replacement care arrangements didn't work out, look for an alternative. Don't give up.

Building your plan to improve your sleep



Irene and I are up most nights with Alice. Lately, she seems to catch everything in the winter months – it's not a cold, it's another bout of tonsillitis, which has her up coughing throughout the night. Sometimes the coughing gets so bad she ends up vomiting because of all the trapped mucous. As a result, none of us is getting any sleep.

All of this sleep deprivation has motivated us to develop a plan of attack for the coming weeks:

1. We are taking Alice to our GP for a review just in case there is anything else we could be doing.
2. Irene and I have discussed planning a better evening and bedtime routine for the house.
3. We are working on a daily activity sheet for some upcoming overnight respite we have booked for Alice for when she is feeling better.
4. We are also planning to talk to Alice about the respite once all the details are finalised so we can set it up for success.
5. We have learned from this module and our friends' experiences that the first time never goes quite to plan, so we are also planning to review the plan and see what needs to be tweaked for next time.

Jack (42) and Irene (40), parents to three children, including Alice (7) with autism

Putting your plan into action

It is important that you prioritise your sleep.

It might take a bit of trial and error to get to the bottom of why you, and perhaps the person you care for, aren't getting enough sleep but the time and effort will be worth it.

When you're putting your plan into action:

- spend time with positive people who will encourage you to look after your health and wellbeing
- say no if your days become overloaded (a resource is included in the Additional resources)
- think twice before taking on extra commitments – you are already doing enough (if not too much)
- start small and build up
- let others support you and the person you care for.

Make 'me' time a priority. Remind yourself that:

- the person you care for will soon get used to the new routine
- you are a team and you both have needs that require attention.

Be prepared for little things to go wrong. Whatever happens, you and the person you care for will manage it.

Celebrate your successes, even the small successes. Be kind to yourself if the plan didn't go quite as you'd hoped. Sometimes plans need refining.

Don't forget to review your plan. You can redo the module as often as you want.



I've tried telling him for months he needs to see his doctor about his sleep – but he's sick of doctors and gets cross with me every time I raise it. The kids have offered to talk with him this time, and ... I'm going to let them. I know he is sick of specialists, but he needs to go, and the kids helping is taking a load off me. Hopefully he will listen to the kids, because I think we will all benefit from more sleep.

Mary (57), carer to her husband with MS and her father-in-law with dementia

Congratulations



Congratulations!

You've completed the sleep module!



Learning summary

Having completed the sleep module you should now:

- ✓ have a better understanding of sleep and its importance to your health and wellbeing
- ✓ know whether or not you are getting enough sleep and what to do about it
- ✓ have developed strategies to manage your day after poor or no sleep
- ✓ have created your care team
- ✓ have developed your plan to improve your sleep
- ✓ have committed to putting your plan into action

Additional resources



The following resources have been developed:

- Duty of care
 - Home safety checklist
 - Other safety issues checklist
- Common medical causes of sleep disruption
- Is the person you care for disturbing your sleep?
- National Sleep Foundation sleep diary
 - <https://www.sleepfoundation.org/sites/default/files/inline-files/SleepDiaryv6.pdf>
- Making sleep a priority
- Good sleep habits for carers
- Worry time
- Sleep in young carers
- All the ways to get sleep – sleep strategies
- Replacement care
- How family and friends can help
- Care plan template
 - Daily routine template
- Learning to say 'no'

The Sleep Health Foundation has the following resources:

- ageing and sleep
<https://www.sleephealthfoundation.org.au/older-people-and-sleeping.html>
- anxiety and sleep
<https://www.sleephealthfoundation.org.au/anxietyandsleep.html>
- caffeine and sleep
<https://www.sleephealthfoundation.org.au/caffeine-and-sleep.html>
- caffeine, food, alcohol, smoking and sleep
<https://www.sleephealthfoundation.org.au/caffeine-food-alcohol-smoking-and-sleep.html>
- central sleep apnoea
<https://www.sleephealthfoundation.org.au/central-sleep-apnea.html>
- depression and sleep
<https://www.sleephealthfoundation.org.au/depression-and-sleep.html>
- excessive daytime sleepiness
<https://www.sleephealthfoundation.org.au/excessive-daytime-sleepiness.html>
- herbal remedies and sleep
<https://www.sleephealthfoundation.org.au/herbal-remedies-and-sleep.html>
- incontinence (nocturia) – the need to get up during the night to urinate
<https://www.sleephealthfoundation.org.au/incontinence.html>
- insomnia
<https://www.sleephealthfoundation.org.au/insomnia.html>
- melatonin
<https://www.sleephealthfoundation.org.au/melatonin.html>

Additional resources



- menopause and sleep
<https://www.sleephealthfoundation.org.au/menopause-and-sleep.html>
- menstrual cycle and sleep
<https://www.sleephealthfoundation.org.au/menstrual-cycle-and-sleep.html>
- obstructive sleep apnoea
<https://www.sleephealthfoundation.org.au/obstructive-sleep-apnea.html>
- restless legs syndrome
<https://www.sleephealthfoundation.org.au/restless-legs-syndrome-rls.html>

Carer Gateway also has the following resources:

- What is respite care
<https://www.carergateway.gov.au/what-is-respite-care>
- Who can get respite
<https://www.carergateway.gov.au/who-can-get-respite>
- Respite at home
<https://www.carergateway.gov.au/respite-at-home>

Other resources

- Department of Veterans' Affairs Highres healthy sleeping tool
<https://highres.dva.gov.au/highres/#!/tools/healthy-sleeping>
- Headspace:
 - Sleep by Headspace
<https://www.headspace.com/sleep-by-headspace>
 - meditation for sleep
<https://www.headspace.com/meditation/sleep>

Young carers

- Reachout:
 - How to get a good night's sleep
<https://au.reachout.com/articles/how-to-get-a-good-nights-sleep>
 - How much sleep do I need
<https://au.reachout.com/articles/how-much-sleep-do-i-need>
 - Chilling out
<https://au.reachout.com/mental-fitness/chilling-out>
 - Recharge app
<https://au.reachout.com/tools-and-apps/recharge>
 - What are sleep problems
<https://au.reachout.com/articles/what-are-sleep-problems>
 - Treatments for sleeping issues
<https://au.reachout.com/articles/treatments-for-sleeping-issues>
 - Insomnia
<https://au.reachout.com/articles/insomnia>
 - Smiling mind
<https://au.reachout.com/tools-and-apps/smiling-mind>
- Headspace:
 - sleep factsheet
<https://headspace.org.au/assets/Factsheets/HSP225-Sleep-Fact-Sheet-DP3.pdf>
 - sleeping well for a healthy headspace
<https://headspace.org.au/young-people/sleeping-well-for-a-healthy-headspace/>
 - how to help your teenager sleep better
<https://headspace.org.au/blog/how-to-help-your-teenager-sleep-better/>

Additional resources



Person being cared for

- Dementia Australia has a range of help sheets <https://www.dementia.org.au/resources/help-sheets>, including:
 - Caring for someone with dementia – Sleeping
https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone16-Sleeping_english.pdf
 - Caring for someone with dementia – Safety issues
https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone03-SafetyIssues_english.pdf
 - Caring for someone with dementia – Continence
https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone18-Continence_english.pdf
 - Changed behaviours and dementia – Wandering
https://www.dementia.org.au/files/helpsheets/Helpsheet-ChangedBehaviours04-Wandering_english.pdf
 - Changed behaviours and dementia – Sundowning
https://www.dementia.org.au/files/helpsheets/Helpsheet-ChangedBehaviours05-Sundowning_english.pdf
- Cancer Council of Australia – Caring for someone with cancer
<https://www.cancercouncil.com.au/get-support/caring-for-someone-with-cancer/>
- Parkinson's disease
<https://www.parkinsons.org.au/information-sheets>, including:
 - Sleep and Parkinson's
https://docs.wixstatic.com/ugd/bfe057_8bd09830cdef4d6781b2aaf7932c56d0.pdf
- Relationships and Parkinson's
https://docs.wixstatic.com/ugd/bfe057_d23936f0d44640208d34a4ab3d2fe45c.pdf

Home safety checklist

It is important to have a falls hazard free home, especially if:

- the person you care for has a mobility or vision impairment
- services are provided in the person being cared for's home.

Research shows that about 25 per cent of all injuries in Australia requiring hospitalisation occur in or around the home. Many of these accidents are preventable.

Falls are the leading cause of hospitalisation injuries in Australia. Young children and the elderly are most at risk of falls but teenagers and adults are at risk too.

Checklist

The checklist helps you identify potential hazards in each room and makes suggestions about how to fix the problem.

Floors – look at the floor in each room

- *When you walk through a room, do you have to walk around furniture?*

Move the furniture so the path is clear.

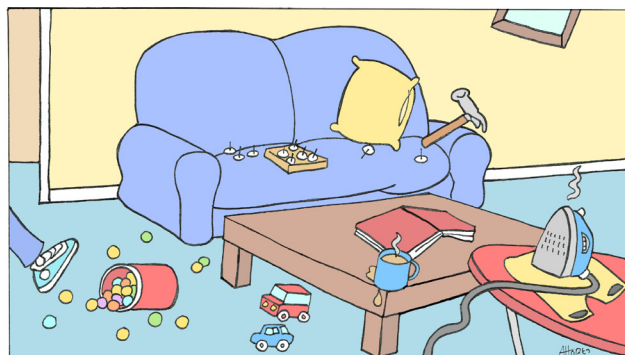
- *Are the floor coverings non-slip and in good condition?*

Torn carpets, carpet joins, loose tiles, polished floors and tiles can cause slips and trips. Repair damaged carpets and tiles, either remove rugs/mats or anchor with double-sided tape and use slip resistant treatments on the walkways.

- *Are there rugs/mats on the floor?*

Remove the rugs/mats or use double-sided tape or a non-slip backing so they won't slip.

- *Is there uneven flooring?*



Install mini-ramps for uneven flooring at doors and use coloured tape to alert people to changes in floor surfaces.

- *Do you walk over or around wires or cords such as lamp, telephone or extension cords?*

Coil or tape cords and wires next to the wall. You may need an electrician to put in another outlet.

Stairs and steps – both inside and outside

- *Are the stairs and steps safe?*

Check and repair any stairs and steps that are not too high or narrow, uneven, loose or broken. If you have patterned or hard to see steps or stairs think about putting non-slip contrast tape or paint the edges.

- *Is the carpet or floor covering on the steps loose or torn?*

Make sure the carpet or floor covering is firmly attached to every step or remove the carpet/floor covering and attach non-slip rubber treads to the stairs.

- *Are the handrails loose or broken?*

Home safety checklist

Repair loose handrails or install new ones. Request an occupational therapy home assessment to ascertain if handrails are needed on both sides of the stairs.

- *Is a ramp needed?*

Request an occupational therapy home assessment to ascertain if a ramp is needed. If one is already in place make sure it is sturdy, safe and well maintained.

- *Is there sufficient lighting?*

Stairwells should be fitted with globes of at least 75 watts. Replace blown bulbs immediately. Install additional lighting if required.

- *Is there a light switch at both ends of the stairs?*

If not, install switches at the top and bottom or sensor lighting.

- *Is there clutter on or around the stairs?*

Make sure the stairs and stairwell are free from objects and clutter at all times.

Kitchen and eating area

- *Are the cupboards too high, low or deep?*

Install adjustable shelving that swings up, down or rolls out. Move things you use often to the most easily accessible shelving.

- *Are pathways obstructed?*

Make sure pathways are free from objects and clutter at all times.

- *Is the lighting adequate?*

If not increase wattage of bulbs or ask an electrician to install more lighting.

- *Is the floor slippery?*

Clean up spills straight away. Use slip resistant treatment on the floor or change flooring to one with a less slippery surface.



Bathrooms

- *Is the bath tub or shower floor slippery?*

Put a non-slip rubber mat or self-stick strips on the floor of the tub or shower.

- *Is there a step into the shower?*

Remove the threshold from the shower to make it a step-free, walk-in shower.

- *Are there sufficient grab rails?*

Install grab rails near the bath tub, shower and toilet.

- *Is there an adjustable shower head?*

An adjustable shower head can be used sitting or standing and makes cleaning the shower easier.

- *Shower seat*

Purchase a shower seat if required.

Home safety checklist



Bedrooms

- *Is there too much furniture/furnishings/clutter and not enough space to move around?*

Remove excess furniture/furnishings/clutter for easier access.

- *Is the light near the bed hard to reach?*

Place a lamp on the bedside table where it's easy to reach.

- *Is the path from the bed to the bathroom dark?*

Put in a night-light so people can see where they're walking. Some night-lights go on by themselves after dark.

- *Is there adequate lighting?*

Bedrooms should be fitted with globes of at least 100 watts. Replace blown bulbs immediately. Install additional lighting if required.

- *Is the bed too high or too low?*

The bed is too low if a person's knees are above the hips when sitting on the bed. Bed raisers under bed legs can raise the height and make it easier to get in and out of.

The bed is too high when legs do not touch the floor when sitting on the edge of the bed. Remove the bed frame or use a lower profile mattress or box springs.

- *Is there a telephone in the bedroom?*

Invest in a cordless phone or keep a mobile phone on the bedside table or use an emergency alert system.

Living

- *Is there too much furniture/furnishings/clutter and not enough space to move around?*

Remove excess furniture/furnishings/clutter for easier access.

- *Is the furniture steady, comfortable and easy to get in and out of?*

Check and replace or repair furniture to make sure it is stable, practical and safe, especially wobbly arms or legs of chairs. If the seat is too low add a cushion or pillow on the seat to raise the height.

- *Is there adequate lighting?*

Increase wattage for lamps and lights. Replace blown bulbs immediately. Install additional lighting if required.

Hallway

- *Is there a working smoke alarm?*

Install new smoke detector batteries once a year.

- *Is there adequate lighting?*

Increase wattage for lamps and lights. Replace blown bulbs immediately. Install additional lighting if required.

Outdoors

- *Are the footpaths and entrances safe?*

Remove damaged pavers, slip hazards and pot plants and trim overgrown plants from walkways, including around the clothes line.

- *Is there adequate lighting?*

Install sensor lights at the major entry points.

Home safety checklist



Other

- *Are drawers and cupboards over-filled?*

It might be a good time to:

- clean out drawers and cupboards of things no longer worn, used or needed
- store regularly used items in easily accessible places
- if necessary, invest in more practical storage solutions.

- *Are you replacing any furniture?*

If you decide to replace furniture think about:

- how easy it is to move, for example dining chairs need to be easily moved to sit in
- how sturdy it is, for example it needs to be able to withstand the weight of the person being cared for
- purchasing items with no sharp edges such as coffee tables, tables etc.

- *Are there any low hanging lights?*

Low hanging lights can be a problem for tall people. It might be a good idea to shorten the cord of any low hanging lights.

- *Are the electrical fittings and power boards safe?*

Repair or replace any damaged or faulty power points, power boards and extension leads. Do not overload power boards.

What actions do I need to take

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Other safety issues checklist

There are a number of other things you might want to think about for the safety of the person you care for, yourself and alternate carers.

This resource has been developed to give you a starting point.

Equipment for the person being cared for such as lifting equipment and wheelchairs

Make sure all:

- equipment is fit for purpose, for example does it meet the needs of the person being cared for and the carer
- equipment is in good working order and well maintained
- carers know how to use, maintain and store the equipment.

Biological hazards, including human blood and body substances

Biological hazards can expose the person being cared for and carers to infection risks. The risk can be minimised by:

- following good personal hygiene practices, particularly hand hygiene
- if appropriate, using personal protective equipment such as gloves, plastic aprons and closed shoes
- maintaining a clean environment and appropriately managing spills of blood and body substances
- safe handling and disposal of sharps and using retractable needles where appropriate
- hygienically handling and laundering soiled bedding, towels, clothing etc



- handling and disposing of all waste appropriately, including clinical waste
- correctly processing reusable equipment and instruments
- providing training to all alternate carers
- requiring alternate carers to be appropriately immunised (see vaccinations below)
- providing adequate supplies of personal protective equipment, for example gloves in a range of sizes.

Other safety issues checklist

Vaccinations

The Australian Immunisation Handbook recommends that carers have the following vaccinations:

- diphtheria-tetanus
- measles-mumps-rubella
- hepatitis A
- hepatitis B
- flu.

Check with your GP about which vaccinations you, the person you care for and alternate carers require and make sure everyone is fully immunised.

Electrical equipment

Make sure electrical equipment (for example vacuum cleaner, kettle, microwave, washing machine and dryer) are:

- in good working order
- well-maintained
- used and stored appropriately.

Footwear

It is important to wear good footwear when caring for someone. Make sure your and alternate carers footwear is:

- suitable for the type of work and work environment, for example a strong, sturdy closed shoe rather than thongs or sandals
- comfortable with an appropriate non-slip sole and tread pattern
- checked regularly to make sure treads are not worn away or clogged
- designed to provide adequate support and stability.



Hazardous substances and chemicals

There are a number of cleaning and laundry chemicals which can be harmful, especially products containing bleach (sodium hypochlorite) or caustic soda (sodium hydroxide). Disinfectants and cleaning solutions are a common cause of chemical injuries in the home.

When using hazardous substances and chemicals reduce the risk of inhalation, ingestion or skin contact by making sure anyone using the products:

- reads, understands and adheres to the product safety information on the container
- uses the lowest concentration of the hazardous ingredients which will still do the job
- wears appropriate protective clothing such as rubber gloves and masks
- makes sure that confined spaces are well ventilated when using some types of chemicals
- uses the products only for their intended purpose
- understands the consequences of exposure, first aid and any emergency response actions
- stores the products safely.

Other safety issues checklist



Vehicles

If you or alternate carers transport the person being cared for, minimise the risk by making sure:

- the vehicle is safe and fit for purpose
- the vehicle is well maintained, especially tyres, brakes and lights
- there is nothing unrestrained in the vehicle
- drivers know how to safely operate the vehicle
- drivers are competent and fit to drive, for example they are licensed and they advise you of any driving offences which may affect their ability to drive
- drivers are trained in how to transport the person being cared for, for example have access to mechanical aids, if required, and/or have appropriate help at the start and end of the journey.

Pets

Pets make great companions and there is a growing trend in using assistive dogs. Dogs, especially large breeds, can be a falls hazard for the frail elderly, people with vision impairment and people with poor mobility. To minimise the risk of harm:

- do not put water and food bowls and litter trays in walkways
- immediately clean up any spillages (potential slip hazards)
- appropriately dispose of biological waste.

Challenging behaviour

Some people being cared for have challenging behaviour, for example:

- biting, spitting, scratching, hitting, kicking
- throwing things
- pushing, shoving, tripping, grabbing and more serious assault
- verbal threats.

Minimise the risk of harm by:

- developing and implementing preventative, de-escalation and avoidance strategies and the steps to be taken if an incident occurs
- making sure all carers are aware of the challenging behaviour, its triggers, the frequency and what to do if an incident occurs
- making sure relevant information about the person being cared for is communicated, especially during handovers.

Care plan

Many people being cared for have a care plan that identifies their specific needs. It is important that the plan is:

- regularly reviewed and updated
- provided to carers and that they understand and follow it.

Other safety issues checklist



Procedures manual

If you are a carer or person being cared for who self-manages their funding you could have duty of care obligations as an employer. As an employer you have a legal obligation to provide a safe working environment.

If you are an employer developing a procedures manual could be helpful to make sure everyone has a clear understanding of the situation, their roles and responsibilities and how things should be done.

The manual could include:

- the person being cared for's care plan
- instructions on how to use equipment and chemicals
- the correct handling of biological hazards
- safety information for both the employee and the person being cared for
- other relevant information.

What actions do I need to take

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Common medical causes of sleep disruption

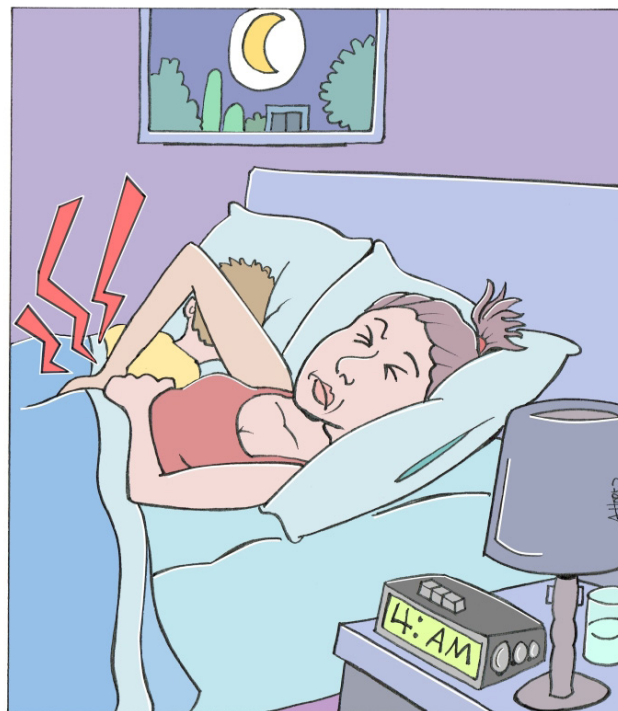
Sleep disruption is widespread and has many potential causes. You may not know that some common diseases/conditions and medications can impact your sleep, or the sleep of the person you care for.

Further information about common physical conditions, neurological disorders, mental health disorders, medications and sleep disorders that can affect the quantity or quality of your sleep is provided below.

Physical conditions

Physical conditions which can disrupt sleep include:

- chronic pain, such as arthritis
- conditions which affect breathing, such as asthma, congestive heart failure and chronic obstructive pulmonary diseases
- diabetes – people:
 - whose blood sugar levels are not well controlled can suffer from night sweats, a frequent need to urinate or symptoms of low blood sugar
 - with damaged nerves in the legs can cause night-time movements or pain
- menopause
- overactive or underactive thyroid function
- heartburn or reflux
- conditions that increase urinary frequency, such as heart failure, diabetes, multiple sclerosis and enlarged prostate
- kidney disease.



Neurological disorders

Some brain and nerve disorders can contribute to sleeplessness, including:

- dementia – wandering, disorientation and agitation during the evening and night
- epilepsy:
 - brain wave disturbances can cause seizures that can affect sleep
 - sleep deprivation can trigger a seizure
- headaches and migraines
- Parkinson's disease.

Common medical causes of sleep disruption

Mental health disorders

Sleep disruption is common with people with mental health disorders including:

- anxiety
- chronic stress
- depression
- phobias
- panic attacks
- bipolar disorder
- schizophrenia.

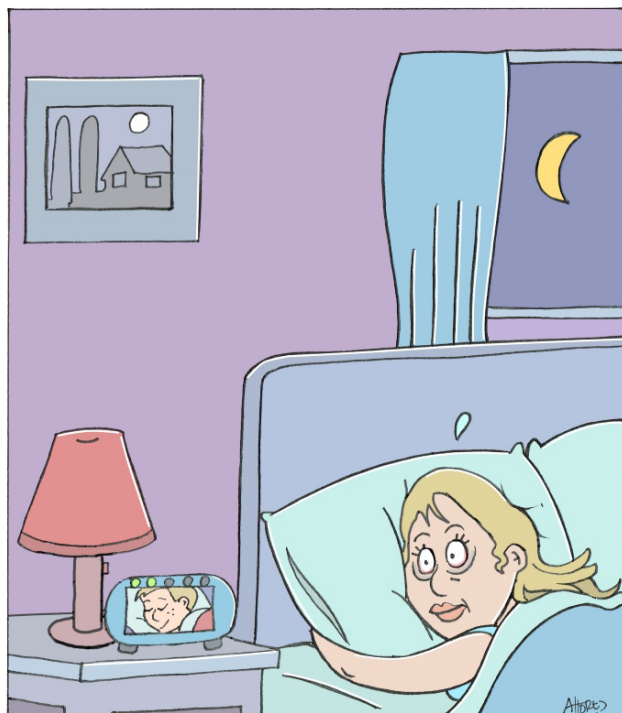
Medications

There are a number of medications, prescription and over-the-counter, which can interfere with sleep, including:

- some Beta blockers, which are used to treat heart conditions
- some high blood pressure medications
- medications containing alcohol, for example cough, cold and flu
- medications containing caffeine
- nicotine replacement products
- some depression and anxiety medications
- some attention deficit disorder medications
- some asthma and chronic obstructive pulmonary disease medications
- some inflammation medications.

What to do

If you think there might be a medical cause affecting the quantity or quality of your sleep you should make an appointment with your doctor as soon as possible.



Turns out the insomnia might also be related to my menopause. Now that I know this I have been logging my symptoms to discuss with my GP at my next appointment.

Joanna (57), started caring for her friend, Ivy (79), who has heart disease, breast cancer and a suspected cognitive impairment. Joanna lives with her husband, Rob (66).

Is the person you care for disturbing your sleep

Many care recipients have disturbed sleep. For example, they:

- do not sleep well because of:
 - poor sleep habits
 - worry or stress
 - nightmares
 - their health condition
 - sleeping irregular hours, for example it is common for people with psychosis to sleep too little or too much
 - pain and discomfort
 - having an undiagnosed sleep disorder
- have behaviours which disturb your sleep, for example needing toileting help, restlessness, wandering, kicking, touching, requests for attention/help, sleep talking or wanting to get dressed
- are dependent on technology, for example ventilator, oxygen, pump, dialysis, and you need to be alert to and respond to alarms
- need to be monitored during the night, for example blood glucose levels, epileptic fits
- require night-time care, for example changing postures, medication management or pain management.



Poor sleep habits or behaviours

If the reason for your sleep disruption is because the person you care for has poor sleep, or behaviours which disrupt your sleep:

- it might be as little as introducing better sleep habits
- you could help the person you care for develop strategies to reduce their worry or stress (see "For more information" below)
- you could learn more about how their health condition impacts on their sleep (see "For more information" below)
- if you think there is a medical reason for their sleep disruption make an appointment with their GP or specialist as soon as possible to identify and treat the symptoms.

Is the person you care for disturbing your sleep



Reading this module helped me realise that Liz and I both had poor sleep habits. Liz and I worked through the module together and we developed a new relaxing bedtime routine and we can't believe how much it has helped. We feel so much better and have more energy.

Megan (44), mother of two, working full-time and carer to her sister, Liz (44) who has Down Syndrome

Other things that interfere with your and the person you care for's sleep

- In situations where your sleep continues to be disturbed you can:
- create a care team (**see page 22**) to support you and the person you care for, either through providing occasional or regular overnight care or helping with household and other tasks
- arrange for the person you care for to be assessed by an occupational therapist, especially in relation to monitoring devices, assistive technology or assistive animals
- develop strategies to help you manage your day after poor sleep (**see page 19**)
- if the person you care for is a NDIS client, talk to your NDIS planner or support coordinator about the impact of your sleep deprivation on your ability to provide care.

Sharing information and tips

Sharing information on specific, practical strategies for coping is helpful, especially for new carers. You can do this by contacting your state or territory carer association or condition specific support group, for example Dementia Australia or Autism Spectrum Australia.

For more information

The following condition-specific factsheets are available:

- Dementia Australia – caring for someone with dementia – sleeping
- Parkinson's Australia – sleep and Parkinson's
- Sleep Health Foundation:
 - Schizophrenia and sleep
 - Post Traumatic Stress Disorder (PTSD) and sleep
 - Anxiety and sleep
 - Depression and sleep
 - Dementia
 - Chronic Fatigue Syndrome and sleep
 - Insomnia
 - Central sleep apnoea
 - Incontinence (nocturia)
 - Restless legs syndrome
 - Excessive daytime sleepiness
 - herbal remedies and sleep
 - melatonin.

Is the person you care for disturbing your sleep



How does the person I care for disturb my sleep?

Once you have identified how the person you care for disturbs your sleep, group them into what you can and can't control. When you do this exercise, really challenge your thinking about what you think you can and can't control.

What do I need to follow-up?

Making sleep a priority

Sleep is as important to our health and well-being as diet and exercise. Without adequate sleep on a regular basis, it is difficult to live well. We may:

- have trouble concentrating and making decisions
- feel sad or irritable
- have a higher risk of accidents and injuries.

For many people, when life gets busy or stressful, sleep is one of the first aspects of health to take a 'back seat'. For carers, this is often the reality of their caring role.

The nature of being a carer makes it difficult to prioritise sleep, but we know that adequate sleep will make you more alert, improve your ability to make decisions, respond quickly to emergencies or alarms and improve your mood – all tasks that relate directly to your role as a carer.

It is not selfish to find more time for sleep and it will benefit both you and those around you, including the person you care for.

So, how do we find room for more sleep?

- remember that an extra hour of sleep overnight will improve how you feel and go about your daily activities, so take all opportunities to sleep longer or go to bed earlier, as you may not get another chance or have the choice to do so again for a while
- even a short nap can improve sleepiness and performance so it is always worth grabbing a nap whenever you are able to



- put off non-urgent duties or tasks until later or another time – if leaving something until later will cause you worry or stress, it may be better to get it done as it is hard to sleep when your mind won't rest
- if you have the option for help with your caring role, even during the day, think about using that time (or a portion of that time) to take a nap
- use technology to your advantage when preparing for sleep – using a meditation or relaxation app to prepare for sleep, or a white noise app while you are getting to sleep if you find it helps
- where it is safe, think about dimming the lighting in the evenings to promote sleep for everyone in the house
- a key to prioritising sleep could be:
 - let go of worry about where or when you are sleeping, or even for how long
 - just 'take what you can get' and celebrate whatever sleep or rest you get.

Making sleep a priority



After reading this module I made sleep a priority and I'm feeling better for it. I've started waking earlier in the morning so that I can catch a little bit of time to myself before everyone else gets up for the day. I am also trying to get to sleep earlier in the evening – it doesn't always go to plan but I'm trying my best.

Megan (44), mother of two, working full-time and carer to her sister, Liz (43), who has Down Syndrome

Good sleep habits for carers

Many people have trouble with their sleep. In fact, most people will experience periods where they don't sleep well and don't get the sleep they need. This might be due to illness, stress, work patterns, family commitments, sleeping environment, a sleep disorder, pain or a bed partner with poor sleep – lots of things can impact our sleep.

The good news is there are many things you can do to improve your sleep. (see **top ten tips for a good night's sleep SHF**) However, while the guidelines are valuable to keep in mind, as a carer there are many things about your sleep you can't control. Below are some tips for improving your sleep, with some additional things to think about in your role as a carer.

Have a regular sleep pattern

This is common advice but as a carer, it may be impossible to keep a regular sleep pattern when your sleep timing depends on what the person you care for is doing, how they're feeling or what else is going on in your household.

There may be times when good sleep is hard to get because of overnight caring duties. When you can't be certain when your next opportunity for sleep will be and for how long, you should sleep when you can – even if it means having different bedtimes/risetimes.



Spend the right amount of time in bed

Adults need a minimum of seven hours sleep on a regular basis to be at their best and would ideally sleep somewhere between seven and nine hours. Remember that to get at least seven hours sleep you need to be spending close to eight hours in bed. Don't get worried if you can't or if this doesn't happen very often.

While one long sleep at night is ideal, your total sleep per day can be obtained as several smaller sleeps.

Good sleep habits for carers



Be comfortable in your sleeping environment

Ideally, we would sleep at night in a cool, darkened bedroom with minimal noise, on a comfortable bed. However, if you find it easier to sleep sitting up in a chair or you have 15 minutes to lie down on the couch then you should do that.

If it helps to sleep in the same room as the person you care for, (perhaps it eases your worry to be able to see them all the time) do that. Alternatively, if sleeping in a different room works for you and your circumstances, you should do that.

The most important person in deciding where to sleep is you – find what works for you and your sleep and know this may change with changing circumstances.

Wind down and relax before going to bed

Having a relaxing bedtime routine can be helpful in getting to sleep, no matter what the time. While you may not be able to establish a long, regular routine every night, the following suggestions can help you get 'ready' for sleep:

- having time away from screens (phones, television, computer)
- taking a few minutes to listen to some quiet music
- reading a book
- writing about your day
- doing some relaxation or mindfulness – you may have an app that can guide you through this.

Different things work for different people. Find what works for you and stick with it.

You may have trouble switching off your thoughts. Remember that we can never completely shut off our mind. Our thoughts continue all the time but if this is a problem for you, a worry time resource has been developed to help you manage your worries so they don't disturb your sleep.

Before going to bed, you could write some things down – a 'to do' list for the next day, or things you don't want to forget and then don't think about these things until the next day.

Good sleep habits for carers



Know the effects of alcohol, caffeine and cigarettes

Caffeine can be effective at improving your alertness for a short time but because of this, should be avoided for at least four hours before going to bed, as it can make falling asleep difficult. Given that you may need caffeine (which is found in coffee, tea, energy drinks and colas) to improve your alertness either during the day or at night, be aware of balancing both your alertness and sleep needs.

Alcohol can impact your sleep, and while it often feels like it may help with falling asleep, it makes:

- it harder to stay asleep the whole night
- sleep problems like snoring and sleep apnoea worse.

Smoking also makes it difficult to go to sleep, so if possible avoid cigarettes before going to bed and during the night.

Don't lie awake watching the clock

If you are not asleep within 20 to 30 minutes of going to bed you should get up. Sleep is not something you can force. Try sitting in another room, in subdued lighting, quietly reading but not watching TV, or using your phone or computer.

When you feel tired and sleepy again, go back to bed. This helps link your bed or sleeping area with sleep in your mind and not with feeling frustrated and not sleeping.

Resting is good – it does not have to be sleep. Try not to label yourself as 'an insomniac' as this can increase worry and frustration.

Carefully consider the use of sleeping pills

Sleeping pills are something that should always be used in consultation with your GP. There may be circumstances where their use is required but remember that they should be considered for short term use only and do not actually 'solve' your sleep problems.

You may want to think about how taking sleep medication will affect your ability to care overnight – will you wake and be alert enough if you are required? All these things need to be discussed with your GP and other supportive people.

Good sleep habits for carers



You may need professional help

There are many other things that can negatively impact your sleep aside from your caring role.

For example, if you think that you might have a sleep disorder, you may never be able to get enough sleep – even when you do have the opportunity to do so. See your GP to discuss your sleep. They can direct you to a sleep specialist so you can access and learn about the many effective options for treatment.

Re-establishing routine after periods of major disruption

There may be times where your sleep patterns are completely ‘flipped’. For example, if your care recipient has a hospital stay and you stay with them at the hospital – perhaps taking on overnight caring duties.

If this happens, you may find it difficult to simply switch back into ‘dayshift’ mode, particularly if the ‘nightshift’ pattern continues for many weeks. In these circumstances, all of the advice above applies BUT most importantly, give yourself time as it can take a while to settle comfortably back into good sleep patterns and habits.



It has been really helpful to think through all the ways that I can help myself and Jane. I have set up an action plan and sleep routine for us both. We might not be able to control Henry’s (10 month old son) night waking or teething pains, but we can keep each other accountable to having a good wind down routine. I hate to say it – but the first step will be that this coffee lover will be cutting back to only two coffees a day!.

Ian (35), carer to his wife, Jane (28), who has a diagnosis of breast cancer

Worry time

It's a normal part of life to worry from time to time

But too much worry can interfere with our daily lives and disrupt our sleep. We can spend a lot of time worrying about things that:

- never happen
- are out of our control.

Some people worry more than others and there are more effective ways to manage your worry.

Thinking versus worrying

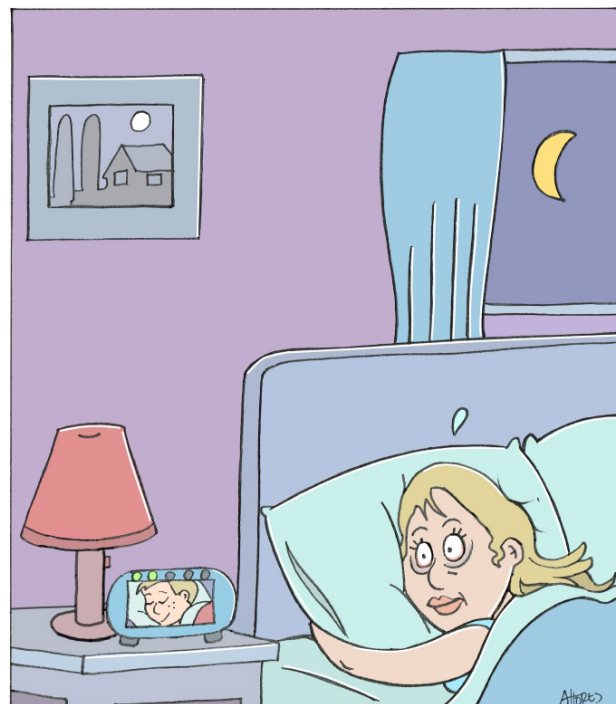
The difference between thinking and worrying is that thinking is about reflection and analysis that leads to action, when action is necessary. Worrying is feeling uneasy or being concerned about a situation or problem.

Excessive worrying is where your mind goes into overdrive with repetitive thoughts, is unhelpful and is common during times of uncertainty.

Thinking takes control over the situation, excessive worrying lets the situation take control over you.

How to worry more effectively

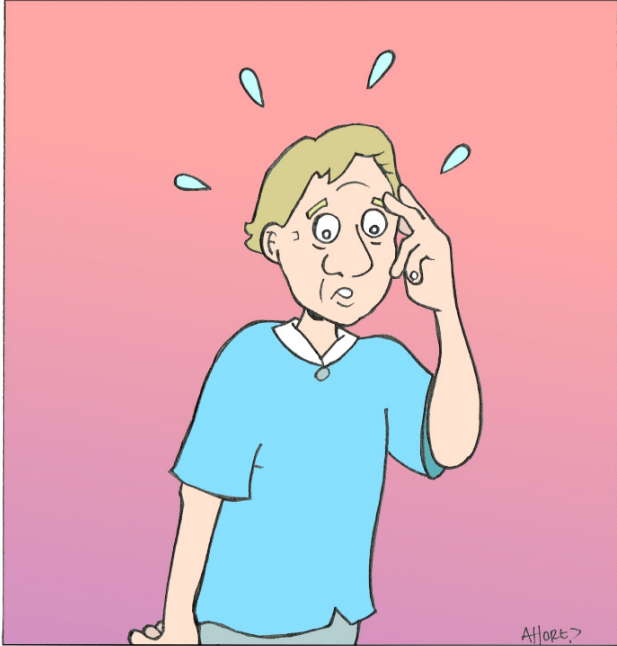
A step-by-step process is outlined below to help you learn to postpone your worries to a dedicated worry (thinking) period. By learning to postpone your worries, they will become less intrusive in your life and you'll manage them more effectively, giving you a greater sense of control.



Step 1 – plan your worry time

- Chose a particular time, place and length of time (10 to 20 minutes) for worrying. These should be the same each day. For example, 3pm, dining room table for 15 minutes
- Make sure you are comfortable and free from distractions, including your mobile phone
- The place needs to be somewhere you go to regularly, like a lounge room chair rather than somewhere you only go to for worry time
- Your worry time should not be scheduled close to bedtime. Try and have at least two hours between worry time and your bedtime.

Worry time



Step 2 – postpone your worry

- As soon as you become aware of a worry, postpone it to worry time by noting it. You can:
 - carry a small notebook with you
 - keep a pad somewhere handy
 - use the notepad function of your mobile phone
- Remind yourself that:
 - you don't need to think about it now because you'll have time to think about it later
 - you'll be in a better position to deal with it during your worry time
 - there are more important or pleasant things to do now

- Refocus on the present moment:
 - pay attention to what you were doing before you were worrying OR
 - do something else to help you let go of the worry until worry time.

Step 3 – worry time

- At your worry time go to your worry place
- Only worry about the things you have written down
- Think about each worry and ask yourself:
 - is this worry helpful? – if the answer is no – stop worrying about it
 - is there anything you can do about it? – if the answer is no – stop worrying about it
- Put the worries you can do something about into priority order
- Spend your remaining time problem-solving the worries you can do something about or, if necessary, make a time to resolve high priority 'worries'
- Sometimes it can be helpful to problem-solve with a friend
- Stop at the end of your allocated worry time, you can resume your worrying again tomorrow.

Practice

Like all new skills, recognising when you're worrying and postponing them to worry time takes practice and patience. However, with practice you can learn to worry more effectively.

Worry time



Bedtime

- If you find yourself worrying at bedtime or while you are trying to go to sleep, remind yourself:
 - you've dealt with your worries as best you can during your worry time
 - you can work on them again during your worry time tomorrow
 - nothing can be done while you are so tired
 - the best thing you can do is get a good night's sleep.
- Keep a pad and pen on your bedside table to note any worries and then refocus on the task at hand – sleeping
- Spend a few minutes thinking about "what have I done today". Focus on at least one positive thought rather than anything negative.

App

ReachOut has developed a WorryTime app. The key features of the app helps you to:

- decide on a time, place and length of time to deal with your worries each day
- when you notice yourself worrying about something, add it to WorryTime and get on with your day
- use your WorryTime and get on with your day
- use your WorryTime to review the worries you've added and ditch the ones that no longer matter to you.



My daughter and I are both finding this technique really useful. The great thing about us both doing it is that we remind each other to save the worry for our 'worry time'.

Cheryl (56), carer and parent to her son, Daniel (33), who abuses substances and her daughter, Lily (29), who has generalised anxiety disorder

Sleep in young carers

Everybody has their own preferences of when they like to go to bed and wake up, as well as how much they would like to sleep.

This variation is normal and is influenced by what else we have going on in our lives, such as work, family and study, but is also driven by our biology. Age is a particularly strong biological influence that will determine how long and when we sleep best.

The main ways sleep differs in younger people from older adults are:

- timing (driven by our internal body clock)
- sleep 'need' – that is how much sleep you need every 24 hours to be at your best.

Sleep timing – influence of the body clock

Teenagers and adolescents often have a 'delayed' body clock – which means it can be easier to fall asleep later (sometimes much later) and wake later too.

This is often misinterpreted as teenagers being 'lazy' and sleeping-in, or being defiant and going to bed late. However, this is actually driven by their biology.

What does this mean for younger carers and what can be done about it? Below are some tips:

- it may be difficult to fall asleep in the early evening. Try not to get worried as this is a natural rhythm of younger people, especially teenagers
- where you do have flexibility with the timing of your sleep – perhaps you could share your caring duties with another person – you could do 'shifts' that align with your sleep preference time



- during times where you are awake early, after a late night, be mindful of how you will feel – for example in the morning, even 8am, you may still be feeling sleepy and groggy, and find it hard to wake up
- if possible, avoid booking appointments early in the morning – instead book for late morning or in the afternoon when you are feeling more alert and in a better position to drive, make decisions and communicate effectively.

Sleep in young carers

Sleep need

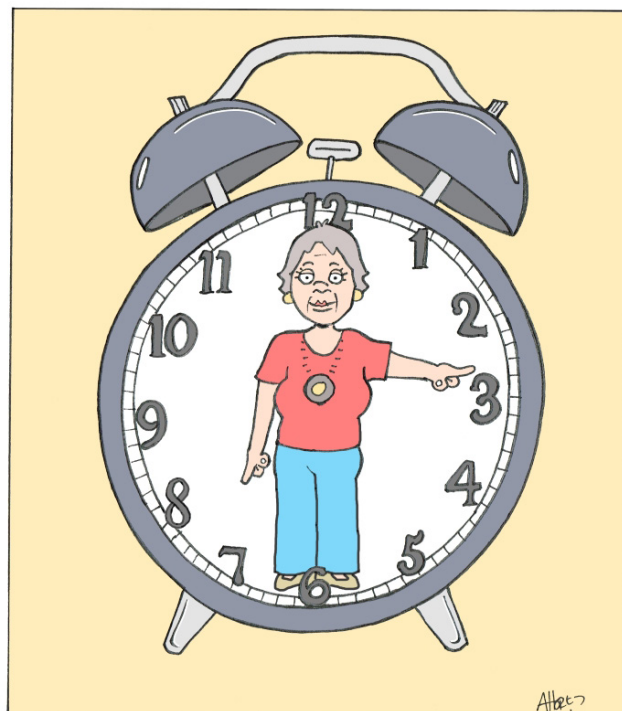
There is large variation in what we call 'sleep need'. Essentially, we know that younger people, up until the age of about 18 to 20 years, need more sleep than older adults – closer to nine to 10 hours (depending on age).

What does this mean for younger carers and what can be done about it? Below are some tips.

It can be reassuring to know that sleep might be contributing to your feelings and behaviour. You might feel sad or irritated or find it hard to do things when you don't get enough sleep. Try improving your sleep by using the tips above and see if that lifts your mood and performance.

*Be aware of how much sleep you are getting night to night. A good way to do this is to track your sleep for a week or two using a **sleep diary** or an app. If you're not sleeping enough, assume that you might not be performing at your best:*

- try and arrange for help one morning so you can sleep longer
- be aware that catching up on sleep by having 'time-out' in the early evening from your caring role might not be a good time for you to be able to fall asleep.



I've always thought of myself as lazy in the morning – but there appears to be more to it than I first thought! It was helpful to learn that my body clock causes me to function better in the day. While I can't control my whole schedule, I'm going to choose later class times to see if this helps with my concentration.

Renee (17), carer to her father (48) with schizophrenia

All the ways to get sleep – sleep strategies



In an ideal world, adults between the ages of 26 to 64 years old would sleep seven to nine hours in one block every night. But this is rarely the case for many Australians.

Carers can be on stand-by for the person they care for 24 hours a day and because of this, may have different sleep patterns.

Shorter sleeps, multiple times across a 24 hour period can still 'add-up' to give you your total sleep each day. Sleep, no matter how short or what time or where, is always worth having.

Below are some beneficial ways to get your total sleep each day when you can't sleep in a seven to nine hour overnight block.

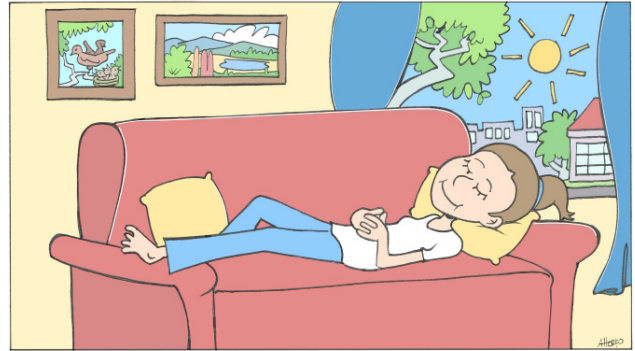
Daytime sleep

While our bodies are programmed in a way that makes sleep at night more natural (easier to fall asleep and stay asleep) daytime sleeps still 'count'.

One of the challenges with daytime sleep is that it may be hard to fall asleep – this is because we are fighting against our biological urge to be awake. However, if you have not slept well or enough in the previous night(s)/days you may be tired enough to fall asleep no matter what the time.

If you plan to sleep during the day, reducing noise and light will help. Think about using:

- ear plugs to block noise or think about using a white noise app or machine (or even a fan next to your bed to create your own white noise)
- block-out window coverings or a sleep mask to reduce the light.



It is also important to adjust your expectations around how long and the quality of your sleep. Daytime sleep tends not to be as long or as 'deep' a sleep as at night.

Naps

Napping can be a good way to improve your alertness and how you feel in between longer sleep opportunities. While longer naps will increase your total sleep for the day, a nap as short as 10 minutes can be beneficial to your alertness.

If you have to be awake at a specific time, set an alarm and keep it close so you won't worry about sleeping through it.

Split sleep (where you plan to get your sleep in multiple blocks)

You may occasionally (or regularly) wake or be woken during the night to administer medications, do medical observations, respond to alerts etc.

If you know this ahead of time, you might choose to 'split your sleep' – that is, plan to get your sleep in two (or more) blocks.

All the ways to get sleep – sleep strategies



You might sleep for a few hours; get up to do what needs to be done such as administer medications; and go back to bed to get some more sleep.

Some things to think about with this approach:

- what you have on the next day
- the likelihood that you can sleep without interruption for your second (or third) block.

If you know you have to be up early, heading back to bed as soon as you can after doing your tasks might be better than taking your time and doing other, quiet things.

Broken sleep (where your waking between sleeps is unplanned)

Waking during sleep is normal, most of us just don't remember our brief awakenings. How much we wake will vary between people but will also vary within the same person from night to night.

As a carer, your sleep may be broken (lots of periods of short and/or longer bouts of wake) due to:

- the needs of the person you care for
- worry or stress
- a medical condition of your own
- needs of other family/individuals in the household
- external factors such as noise, light, weather etc.

Where these things are within your control you should look to ways to reduce the impact they have on your sleep. For example:

- can you wear an eye mask if the lights have to stay on, or it is daytime?
- you or the person you care for could have an undiagnosed sleep disorder that would improve with treatment or advice from your GP.

Where factors are beyond your control, try not to worry about their impact on your sleep, as this worry can often make sleep worse. See if you can adopt some of the above strategies to improve your sleep or re-organise the way you get your sleep.

Sharing the night "shifts"

There might be another person you can share the night shifts with. For example, in the case of a child, rather than one parent doing all the night shifts, both parents could take it in turns to do the night shift.

If there is more than one person you can share the night shifts with, experiment to find out the best "roster" to suit your situation.

Where to sleep

Ideally we would sleep at night in a cool, darkened bedroom with minimal noise, on a comfortable bed. However, if you find it easiest to sleep sitting up in a chair or you have 15 minutes to lie down on the couch, you should do that.

If it helps to sleep in the same room as the person you care for (perhaps it eases your worry to be able to see them all the time) do so – many parents of small children do this for extended periods.

All the ways to get sleep – sleep strategies



Alternatively, if sleeping in a different room works for you and your circumstances, you should do that.

The critical person in this decision-making is you, not the opinions of others. Where the choice is yours, do what is best for your sleep.



I have never been one to nap throughout the day, but now that I need to give Nancy assistance overnight I've started having catch up power naps through the day. My little trick for my brain and body is to place a blanket over the window to make the room dark enough for me to rest.

Tom (67), carer to his wife, Nancy (60), who has a spinal cord injury

Replacement care

We know that 'recovery' sleeps after periods of inadequate sleep can improve how we feel and go about our daily tasks.

Disturbed sleep is common for many carers and using replacement care is an obvious way for carers to 'catch-up' on sleep.

There is no 'one size fits all' approach to the use of replacement care. Below are some suggestions to help you make the best use of replacement care to improve your sleep.

When to use replacement care?

Using replacement care overnight will give you the opportunity for 'protected' sleep at a time when your body is programmed to sleep. Even if you are very tired, you will sleep better (and usually for longer) at night.

If you only have the option of care replacement during the day, think about using that time for a short sleep or to do tasks that might normally keep you from going to bed. Alternatively, use the time for activities that support good sleep health. For example, self-care, physical activity and completing tasks that are otherwise taking time away from sleep.

Location of the replacement care

You may not have choice when it comes to whether the person you care for goes elsewhere or whether someone comes into your home to provide care. If you do have a choice, think about how you will feel if you are not near the person you care for.

For example, if you go elsewhere to try and minimise disturbances during your break, will you worry or stress? Maybe you will worry less



(and therefore sleep better) if you remain near. If you do stay in the home, what strategies will you have in place to minimise disturbance to you?

Handing over care

Does the person you care for have lots of complex care needs or do they take a while to adjust to having someone else look after them?

Think about what sort of 'hand-over' you can do to a replacement carer to minimise the stress and worry for you when you do take time out for yourself. Having a checklist you can use could reduce the time and energy you put into preparing each time. A care plan and daily activity sheet template are included in the resources to the module.

Replacement care

The day after

Where possible, think about what you have on the next day.

For example, you have the choice between two different nights for replacement care. Following one of those nights you have a long drive to a medical appointment. Following the other you have no fixed plans. You might choose to have the protected sleep the night before the long drive.

Your own sleep health

Having time for protected sleep will not result in more or better-quality sleep if you have trouble sleeping. Some things that may cause sleep difficulties are:

- an undiagnosed sleep disorder
- a poor (bright, noisy, too hot/cold, uncomfortable) sleep environment
- consuming caffeine should be avoided for at least four hours before trying to sleep
- technology use (phone, tablet, computer or TV) too close to bedtime.

Identifying and dealing as best you can with things that impact your sleep, independent of your caring role, will help you to make the most of your sleep when you have the option of replacement care.



'To do' list for the replacement carer

Make sure you develop a list of tasks the replacement carer can do, and keep it up to date. For example, they could do quiet tasks such as ironing, mopping floors and making lunches while you have your recovery sleep.

Replacement care



Now that I have found a support worker Con and I like and trust I want to start using them for overnight replacement care. Con needs to be monitored through the night and I just can't do it anymore, not when I'm also waking throughout the night in pain. The worker will monitor Con through the night as needed, and they have even suggested I put together a list of tasks that they can do while we sleep – like folding sheets, folding washing etc. Every little bit helps.

Julia (85), carer to her son, Con (55), who is non-verbal, has an intellectual disability and needs assistance with all activities of daily living

How family and friends can help

You are never strong enough that you don't need help – Cesar Chavez

The main reasons some family and friends may be reluctant to help provide care are:

- they don't realise you need help
- they don't know how to help
- they're scared of doing a bad job
- they live a long way from the person needing care.

Maybe they think you don't need help

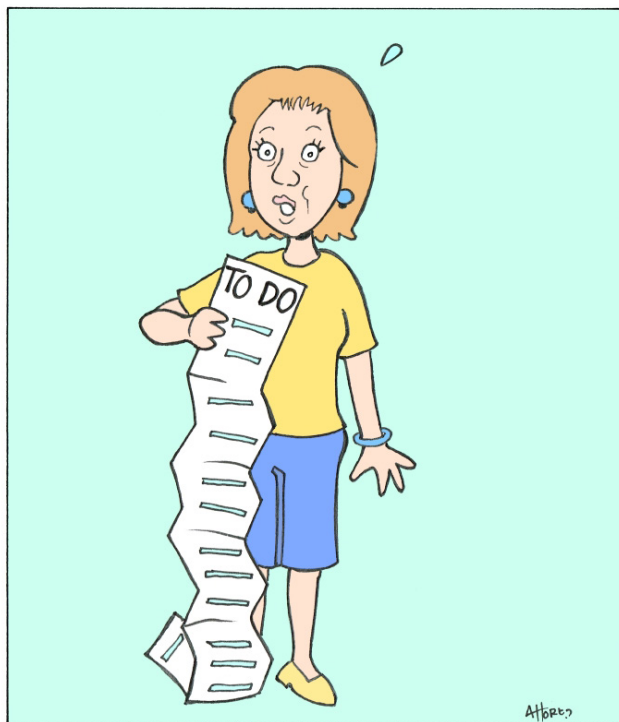
Family and friends are often reluctant to offer to help because:

- from the outside looking in, carers often look as if they have everything under control and don't need help
- they aren't involved in the day-to-day care so they are unaware of how much time and energy is needed to care for your loved one.

One way to let your family and friends know about the extent of your caring role is to arrange a meeting with them to explain it. Family and friends are often shocked to learn just how much carers do.

Other ways to involve family and friends is to let them see first-hand. You can do this by:

- asking your relative or friend to attend a medical or therapy appointment with you and your loved one;
- asking your relative or friend to help with a specific task, for example they could:
 - pick up prescription refills
 - collect your online grocery shopping from the supermarket or do the grocery shopping for you



- help with meal preparation
- help with housework
- pay bills, either online or in-person
- arrange regular social events such as family visits, lunches and picnics
- having them to visit when you would normally be putting the person you care for to bed and asking them to do some of the things you would normally do
- if the person you care for agrees, taking a video on your mobile phone showing the care you provide
- creating a family and friends care group using a private messenger app or Facebook page.

How family and friends can help



This exposure will help your family and friends realise how much time and energy caregiving involves.

They don't know how to help

Some family members and friends do not know how they can help. If this is the case, it is better to ask the person to do specific tasks.

You could write up a list of tasks or activities and your family and friends could nominate which ones they would like to do. If you do this, make sure you include the day and time they need to be completed.

The other option is to ask for help with specific tasks or activities as suggested above.

They're scared of doing a bad job

Some people are reluctant to offer to help because they are afraid they will not do a very good job. They see you as a "professional" carer who knows what you're doing and they may feel inexperienced and clumsy by comparison.

These people might be prepared to help if you slowly ease them into the role and train them in caregiving.

Start out by having them watch while you care for your loved one, which will help them overcome their fear and become familiar with the routine. The more first-hand exposure they have the more comfortable they'll become.

For example, you could invite them over for a meal. While they're there, explain the ways you help your loved one – "I'm cutting up the meat to make it easier to chew", "Let's encourage John to drink his tea so he won't get dehydrated" or "Mum needs a straw with fluids".

Other tips

Other things to remember when sharing the care with family and friends:

- no one is a mind reader – that's why it's important to ask for help when you need it
- when family members become out of touch – with the permission of the person you care for, keep family and friends up-to-date with emails, telephone calls, family meetings and, if appropriate, share any doctor's notes, diagnoses, test results etc
- acknowledge each other's strengths – some people are suited to hands-on care, some are good at running errands and fixing things around the house, others might be great with financial and legal paperwork and some might be good at navigating the healthcare system – match tasks with those most suited to do it
- understand and accept that some family members either won't or can't help
- when the family member or friend lives elsewhere – these people can still contribute, for example by helping with research or paperwork, coming to visit and taking over the care while you have a break, paying bills online etc

How family and friends can help

- don't expect equality in caring, especially amongst siblings caring for parents as typically one or two siblings will often take on the bulk of the care
- be specific when you ask for help – don't assume people will understand what you are asking them to do
- share your loved one's respite care plan and any current problems or worries – when someone doesn't know what's going on they can feel excluded which makes them less likely to help
- if family members do not realise, or are in denial about, your loved one's declining health:
 - give them information about the condition, such as typical symptoms and the type of care they will need
 - meet together with an expert, for example GP, medical specialist or specialist nurse.
- other people do things differently to you:
 - this doesn't mean their way is wrong
 - it could be good for the person you care for to experience different ways of caring.



It was a huge step to move Dad into a nursing home – it isn't what we would normally do in our culture ... but it was no longer safe to keep him at home. At first, I was at the nursing home every day – but it was getting too much for me alone.

This resource got me thinking ... I had thought no one else wanted to help, but it turns out they didn't know how they could help. So, while I still visit regularly, my sister is now taking him home cooked meals, his older sister calls him daily, and his brothers are taking him out on weekly walks.

Every little bit helps ... dad feels more comfortable and I finally have time to recharge between visits.

George (49), carer to father, Rafael (75), who has depression, diabetes and vascular dementia

Daily routine template

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning						
Afternoon						
Evening						

Wake-up routine

Bedtime routine

Night-time wake-ups

Transport

(public transport such as buses, trams and trains, taxis, school bus, modified vehicle etc)

Meal times and medications

Breakfast: xx am –

Lunch: xx pm –

Dinner: xx pm.

1 hour before bed – xx.

Learning to say 'no'

You can be a good person with a kind heart and still say no – Lori Deschene

Do you sometimes wish you could say no? You are not alone. Many people struggle to say 'no'.

You might feel that saying no is uncaring or selfish, or you might fear being disliked or criticised, or that you risk a friendship if you say no.

Many carers have busy lives with little time for themselves. One way to reduce the overload and find some time for yourself is to learn when and how to say no.

Sometimes saying no may be the only way to achieve the best outcome.

Learning to say 'no' is a powerful skill and it takes practise to become comfortable in saying it.

Tips for saying no

Keep your refusal simple. Be firm, polite and brief. You're not asking permission to say no. You don't need to give a reason unless you want to. Use phrases such as "I can't ... my plate is overloaded as it is" or simply "No thank you."

Practice saying no in front of a mirror or in front of a friend. Practicing saying no will help you become more comfortable and confident in saying the word.

Start by saying no to little things, this could be telemarketers or something minor. The more you practice saying no the better equipped you'll be to decline the bigger propositions in life.

Give yourself some time by saying "I'll get back to you". When you've had time to think about it you'll be able to say no more confidently.



Think about a compromise, but only if you want to. Suggest an alternative to suit both of you.

Separate refusal from rejection. You're saying no to a request, not rejecting the person! People usually understand that it's your right to say no, just as it is their right to ask the favour.

Don't feel guilty. It's important for the people around you to hear you say no because it reminds them that you are in charge of setting your boundaries. True friends will respect your boundaries.

Learning to say 'no'



I was so glad to read this information. I have always struggled with saying no, because I really don't want to upset anyone. But, I am exhausted ... I know I've been burning the candle at all ends lately.

My son, John (36), called me at the last minute to babysit the grandkids – and while I would usually drop everything, this time I said a simple “No, sorry John – it's been a crazy week – I need some time out”. I felt bad, but I know it was the best decision for me. I told John that if he gives me more notice next time I will try to help out ... he was fine with that.

Mary (57), carer to her husband with MS, and her father-in-law with dementia