



Sleep and Caregivers

Adequate sleep is essential to staying healthy and functioning well. You need sleep to do your daily work safely, to cope with emotional stress, and to carry on giving care. Yet if you are caring for someone at home or sitting with someone round the clock in a care facility, you likely are not getting enough sleep. Researchers have found that 95% of family members who provide palliative care have serious sleep problems. These problems are becoming better understood, and increased attention is being given to caregivers' sleep problems, especially in those caring for people with cancer, dementia, Parkinson's disease, or children with illnesses or disabilities.

Family caregivers often minimize their sleep problems and hesitate to talk about them with the health care team. You may feel your sleep is less important than what is happening with the person in your care. You may think you can get by with limited sleep and catch up in the future. Unfortunately, this lack of sleep is more likely to catch up with you.

What is sleep disturbance?

Sleep disturbance is any change from the way you usually sleep. It may be a change in how long or how well you sleep, and may include one or more of the following:

- difficulty falling asleep
- difficulty staying asleep through the night
- waking early in the morning
- feeling unrested in the morning
- being sleepy during the day

Factors that contribute to caregiver sleep disturbance

Many factors contribute to poor sleep for caregivers. It may be one or a combination of the following factors:

- **Changes in routine**
When you care for someone, you have less time for fresh air, exercise or relaxation, which promote sleep, and you may consume more caffeine (e.g. coffee, tea, coca cola, chocolate), which inhibits sleep.
- **Change in sleeping environment**
You may sleep on a couch or temporary bed to be near the person you are looking after. You may be disturbed by the nighttime noise made by special equipment, such as an oxygen concentrator, alternating pressure mattress, or even a baby monitor you may use to listen for calls for help.
- **Worry**
You may have trouble falling asleep or may wake up in the night because your mind is busy thinking about your concerns. Some caregivers talk about wanting a remote control to 'shut it off' or 'change the channel'.
- **Lack of help with over-night care**
The programs and services in your area may be limited, which makes it difficult to find respite care at night. You may find it hard to hand over responsibility or trust the care

provided by others. The person who is ill may not be willing to accept outside help.

- **Needs of the person who is ill**

As the person in your care becomes weaker, he or she will need help during the night as well as during the day. Your sleep may be interrupted because you need to help with toileting, repositioning or medications. The person may have trouble sleeping if symptoms such as pain, shortness of breath or restlessness are not well controlled. If the person in your care is unable to sleep, chances are you will be unable to sleep as well.

- **Grief**

You may have trouble sleeping after the death of a loved one. This may be due to poor sleeping habits developed while caregiving, or it may be part of the mental and emotional sifting that happens during the grieving process.

Effects of sleep disturbance

Regardless of the cause, your lack of sleep has consequences for you and for the person in your care. These are some of the common consequences:

- Your overall physical health may change. Your body may not be able to fight off a cold or flu as usual, or you may experience flare-ups of an existing health problem, such as high blood pressure.
- Your overall mental health may change. You may feel less able to cope with the emotional ups and downs and stresses of providing care. You may have memory problems, or trouble thinking clearly. Also, sleep disturbance has been linked with depression.
- Your lack of sleep may change the way you relate to the person you are caring for. You may be impatient, angry or resentful towards the person who is ill, or act in a way you later regret.
- You may feel sleepy or exhausted during the day, and question your ability to carry out day-to-day activities or to provide care safely.

Managing sleep

It is important to talk to the health care team about any sleep difficulties, either yours or those of the person you are caring for. In each case, it is important to ask for the team for help for both your sakes.

Assume that the health care team can control the symptoms of the person you are caring for. Symptoms such as pain, shortness of breath, confusion or restlessness need to be controlled so both of you can sleep. The team needs to hear about difficult symptoms so they can treat them.

Also talk to the health care team about the type and amount of sleep you are getting. Try to be as specific as possible about these points:

- how much sleep you are really getting between the time you go to bed in the evening and the time you wake up in the morning,
- how often you are up in the night as a caregiver,
- how much you rest during the day.

Together, you and the health care team can explore ways to promote sleep and rest. It may help to talk to someone. A hospice volunteer, social worker, spiritual care provider or counsellor may help you find ways to reduce your worries and link you to services and supports.

Many caregivers do not like to take sleep medication, because they worry about not hearing the person they are caring for, or being too sleepy to be provide care in the night. Talk to a doctor about the possibility of taking a sleep medication if other attempts to promote sleep have failed.

Don't be afraid to ask for help with caregiving. Asking for help is not a sign of failure. You do not have to do everything on your own. Sometimes it makes a big difference to ask for even a small bit of help. For example, you can ask someone to cover for you while you take a nap or sleep overnight two or three times a week.

What you can do

These are some things that may help you improve your sleep:

- Try to maintain a regular sleep-wake schedule as much as possible.
- Try to grab even a few minutes every day for exercise and fresh air if at all possible.
- Cut down on caffeine (e.g. coffee, tea, chocolate, coca cola) and nicotine (e.g. smoking) during the day, and especially before bedtime.
- Nap when you can, but try to avoid the late afternoon and evening, unless you know you will be awake during the night to provide care.
- Minimize nighttime noise or light around you. Remove clocks also, unless you need to set an alarm.
- As much as possible, identify, talk about and find ways to address worries and concerns before bedtime. Even small things such as making a list before bed can help clear the mind for sleep.
- Set up a bedtime routine that lets you unwind a bit before you turn out your light. It may help to have a bath, wash your face and hands, change into pajamas, brush your hair and apply lotion to your face and hands.
- Notice what helps you relax, and make that part of your routine. You might listen to soft music, read a bit, watch a funny TV show, or pray.
- It may help to do some relaxation or visualization exercise. Ask your health care team to help you learn how to do this.
- Have something warm to drink or eat before bed.
- Go to bed when you feel drowsy in the evening, rather than making yourself stay up until a set time. This helps you avoid lying awake in bed.

For more information about caregiver needs, see [Module 4](#) of the Caregiver Series.

For additional resources and tools to support you in your caregiving role visit [CaregiversCAN](#).

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