

Helping Her
Manage:

Sleep,
Fatigue, and
Energy Levels

This guide will help you to:

- Understand cancer-related fatigue and how it may be affecting your loved one and you as her caregiver.
- Explore the ways that cancer impacts sleep and energy levels.
- Develop individualized strategies to help manage fatigue and improve sleep.

Cancer can affect both energy levels and sleep in ways that are not always easy to understand.

It is natural to think of sleep, fatigue, and energy levels as being connected. For people with cancer, getting adequate rest and sleep does not always lead to restoration, reduced fatigue, and improved energy levels.

Fatigue

Unlike feelings of tiredness that are part of daily life, fatigue for those with cancer can be described as an overwhelming feeling of tiredness that is not helped by sleep. It can be caused by both the cancer and the treatment, and can lead to changes and limitations in the daily lives of both cancer patients and their caregivers.

You may be surprised and worried about how tired your loved one is feeling. It may upset you to see that she doesn't have enough energy to do daily activities, go to work, or do the things she used to enjoy. You may have to do more because she is too tired. These changes can be hard for both of you.

Small steps, every day.

—Anonymous

Sleep Disturbances

You may also be concerned about your loved one's sleep patterns. For people with cancer, sleep disturbances can include difficulty falling asleep, staying asleep, or waking too early in the morning. Sleep disturbances interfere with getting adequate rest and restoration and can make fatigue and energy problems worse.

While sleep, fatigue and energy levels in cancer can be challenging to deal with, the good news is that these issues can be managed successfully.



How Do Patients with Cancer Describe Their Fatigue and Sleep Problems?

Most people with gynecologic cancer deal with fatigue, reduced energy, and sleep disturbances at some point during and/or after their treatment. These can affect many aspects of your loved one's life, including the ability to resume regular activities. Cancer-related fatigue can cause depression, feelings of hopelessness, and loss of purpose in life. Here are some ways that patients describe problems with fatigue and sleep:

What about you?

Check off any items that your loved one is experiencing. Write in anything else related to fatigue, energy, and sleep

- Less energy and strength
- Less interest in normal activities
- Difficulty participating in regular activities
- Problems concentrating
- The need to sleep more than usual
- Feeling of heaviness in the body
- Not feeling rested even after sleeping
- Feeling weak and worn out
- Excessive exhaustion

What Causes Fatigue?

Cancer-related fatigue can come on quickly. It may last for a short time or for months during diagnosis and treatment, and even beyond the end of treatment. Although the exact causes differ between people, many things can contribute to cancer-related fatigue.

The Cancer Itself

Those with gynecologic cancer may experience fatigue from the cancer itself that may come and go, with spurts of energy at times and prolonged periods of fatigue at others. This can interfere with their livelihood and ability to do things they find fulfilling, such as social activities.

I've come to realize some fatigue will be present even a year after treatment ends... that was something I didn't know. It made me less frustrated after I heard that.

Side Effects of Treatment

Chemotherapy can often lead to fatigue. Combinations of chemotherapy and radiation therapy given at the same time can make fatigue worse. Other symptoms or side effects can also increase fatigue, including pain, problems sleeping, and depression, anxiety, or worry.

Other Possible Causes

- Lack of physical activity
- Too much time in bed
- Not eating the right foods
- Medicines
- Medical conditions, such as low blood counts (anemia), high blood pressure, or diabetes

What Causes Sleep Disturbances?

During cancer and cancer treatment, sleep can be affected by factors such as:

- Anxiety, depression or intrusive thoughts at night
- Pain that is not well-controlled
- Medicines with stimulating effect or side effect (such as steroids)
- Gastrointestinal (stomach) problems such as reflux, nausea, or vomiting
- Frequent urges to urinate
- Hot flashes during the night

YOUR THOUGHTS

In what ways have fatigue and sleep problems impacted your loved one?

How do these problems affect you and your family on a daily basis?

What are some of the **biggest barriers** to managing these problems?

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____

Now, let's explore some strategies and ways to help you overcome these barriers.

Strategies for Managing Fatigue and Energy Levels

The most important thing to understand about cancer-related fatigue is that it is REAL. Fatigue needs to be taken seriously by patients, caregivers, family and friends, and health care providers. Here you can explore different types of strategies to help reduce fatigue. Pick those that you think may work for you and your loved one and help overcome your biggest barriers.

What's Causing Fatigue?

First, figure out what is causing your loved one's fatigue. Some causes (such as sleep problems, pain, depression, side effects from other medications, and anemia) can be detected through a medical evaluation. For example, if the cause of fatigue is anemia (a low number of red blood cells), then treating the anemia will reduce fatigue.

Once other medical conditions are addressed, there may be additional strategies that you can use to improve fatigue. A good place to start is to understand **how** and **when** fatigue occurs.

Rate the Fatigue. Ask your loved one to tell you how it feels and how bad it is for her. Use a 0 to 10 scale, where 0 means “no fatigue”, and 10 means the “worst fatigue you can imagine.” Some find it easier to use a simpler rating of “none, mild, moderate, or severe.” This can help characterize your loved one's fatigue and can provide a way of monitoring changes in fatigue over time.

Track the Fatigue. Tracking your loved one's fatigue through a symptom diary or a log book will help you both get a better picture of the fatigue. It can show patterns of when she has more or less energy. This can help you identify and avoid activities that seem to make your loved one more tired, and schedule activities during times of the day when she has the most energy. A variety of symptom diary formats can be found online for you to use in tracking your loved one's fatigue.



Tracking fatigue can help you answer these questions:

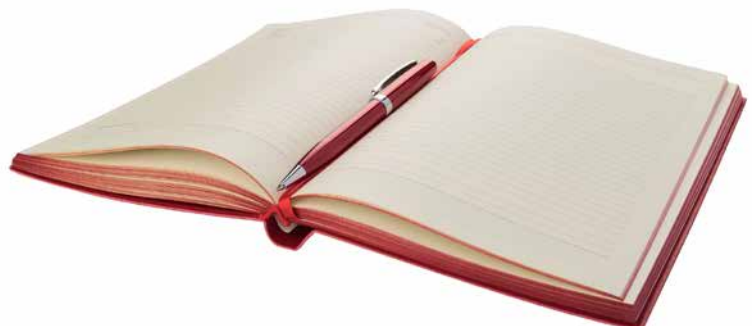
Are there patterns to the fatigue during the day?

Are there patterns to the fatigue during the week?

What is happening when the fatigue is at its worst?

Are there activities or times of day that seem to tire your loved one out more?

What seems to help make the fatigue better?





Get Physical Activity

Finding ways to help your loved one maintain her physical activity is actually one of the best ways to reduce fatigue. The idea of being active may seem impossible for someone who is experiencing fatigue. Having a prolonged lack of activity can lead to muscle loss and muscle weakness, which in turn *increases* fatigue and can affect your loved one's ability to function, as well as her sense of independence.

Types of activities. You don't have to go to a gym to be active! Any kind of activity helps, such as:

- Walking around the house
- Doing housework and yard work
- Going shopping

Encourage the type of activity based on your loved one's ability and interests. If she has been inactive for a while, ask her doctor if she can start an exercise program. A physical therapist can also offer guidance on ways to safely increase activity levels.

Start out slowly. Your loved one should start exercising slowly and increase activity as strength and stamina improve. Think about activities that you can do together, such as walking around your home. Add time every week until reaching a goal of **20-30 minutes, 3-5 times per week.**

Exercise Activity: Walking around the house together.

WEEK 1

Take a brief walk 3 days during the week.

WEEK 2

Increase distance walking by taking 2 trips around the house.

Tip: Schedule exercise activities during the time of day when your loved one has the most energy.

WEEKS 4, 5, 6 ...

Add time each week until you can walk for 20-30 minutes at a time, 3-5 days per week. If needed, break up activity into two or three short (at least 10-minute) sessions, rather than one longer session.



Helpful Tip:

Walking is a great way to get exercise. Research shows that 20-30 minutes of moderate exercise (such as walking) 3-5 times a week can reduce fatigue from cancer and treatment. However, more than an hour of exercise a day may make fatigue worse—so don't overdo it!

Practice Energy Conservation — “The 4 P’s”

Energy conservation is one of the most important ways to manage fatigue. It involves figuring out how to do activities in the most efficient way possible. The following principles — called the “**The 4 P’s**” — can help your loved one do more of the things that are important to her. It can help improve strength and energy, too.

Prioritizing. Help your loved one *decide which activities are the most important and enjoyable*. Encourage her to save her energy for those activities. Seek out family members or friends to help with high-energy activities, for example, ask a neighbor to mow the lawn.

Planning. You can help your loved one plan daily activities ahead of time with these tips:

- **Spread out activities through the day.** Schedule important activities for times when she has the most energy.
- **Set small goals.** For example, go to a neighborhood party for 30 minutes instead of a few hours.
- **Organize chores.** Keep everything for a project in one area (such as a basket) to avoid extra trips.
- **Balance activities with plenty of rest and relaxation.**
- **Encourage her to ask for and accept help.**

Pacing. Encourage your loved one to take rests as needed during and between activities. Try not to push her to do more than she is able to do. If you see her starting to feel tired, ask her to stop!

Positioning. Encourage your loved one to conserve energy while doing activities whenever possible, such as:

- **Sit down while doing a task.**
- **Use special equipment if necessary** (for example, walkers, canes, and bathroom handlebars).
- **Set up the house to be as efficient as possible.** For example, place the TV remote, phone, books, and a notepad on a table next to her favorite chair.

Practice Energy Restoration

Encourage your loved one to take time for things she enjoys and that make her feel good. Listening to music, light reading, meditation, spending time with friends and family, and walking in the park are some activities that people with gynecologic cancers have said make them feel less tired. Doing these types of activities for 20-30 minutes, 3-5 times per week can improve energy, alertness, and memory.



Helpful Tip:

Practice “The 4 P’s” to help your loved one conserve energy.

Prioritizing

Planning

Pacing

Positioning

Strategies for Improving Restorative Sleep

As discussed earlier, the fatigue associated with cancer is not always improved by increasing sleep. However, improving sleep may help your loved one feel more restored and have more energy as the day begins. Helping your loved one find ways to get good, restful sleep at night can help.

Consider trying some of the following strategies:

Napping Do's and Don'ts. One way is to limit naps to 1 to 2 per day. Short naps (less than 30 minutes) can be energizing, whereas long ones may leave your loved one feeling more fatigued and may interfere with nighttime sleep. Build in time for breaks that don't involve napping between activities.

Nighttime R&R. Use strategies to help your loved one relax before going to sleep, such as:

- Consume caffeine only in moderation and early in the day (before 4pm).
- Encourage her to take any stimulating medications (such as steroids) early in the day, if possible. Check with the clinic about scheduled times for these medications, if necessary.
- Avoid nicotine and alcohol within several hours of bedtime.
- Limit stimulating activities such as vigorous exercise, work, or TV in the hours prior to bedtime.
- Suggest reading a book or taking a bath before bed.
- Encourage learning and using progressive muscle relaxation or relaxed breathing techniques to reduce tension.
- Encourage using the bed only for sleeping or sexual activity so that it is not associated with other activities such as working, TV, or being sleepless.

If these strategies to improve sleep hygiene do not lead to improvements in your loved one's ability to sleep, ask her cancer care provider for suggestions to help her sleep better.

Fatigue for me is having the desire to do things but not the energy.





Talk with your loved one's Cancer Care Provider if she has signs of anxiety and depression:

- Worrying about the future and facing another day
- Feeling “blue”
- Exhaustion, sleeplessness
- Irritability
- Lack of concentration
- Hopeless or helpless feelings
- Loss of interest or pleasure in usual activities
- Changes in appetite or weight

Control Pain and Emotional Distress

Pain interferes with sleep and can be physically and emotionally exhausting. Good pain management can also be good fatigue management. Talk to the providers in the clinic about the best ways to manage your loved one's pain.

Stress, anxiety and depression can make fatigue worse. There are many different approaches for treating emotional distress. The key is to find the one that works best for your loved one. Research has shown that counseling, medications, and going to support groups can help manage distress. Stress-reduction techniques such as progressive muscle relaxation and relaxation breathing may also be effective for reducing fatigue. If it seems emotions are interfering with your loved one's life; talk with her cancer care provider to help find the right treatment.

Focus on Nutrition

Good nutrition is important for managing fatigue. When your loved one is fatigued, she may have trouble eating (due to fatigue or other symptoms like poor appetite, nausea, vomiting, or feeling full). It can be helpful to eat smaller, more frequent meals. If she is too tired to make food, encourage her to allow someone else to cook, or use frozen or easy-to-prepare foods.

On the other hand, some medicines may make your loved one very hungry (for example, steroids). When possible, try to keep healthy snacks around rather than sweets or other snacks with low nutritional value.

Some general dietary guidelines (unless your loved one's cancer care provider tells you otherwise) to follow are:

- Provide your loved one with access to a balanced diet (including fruits and vegetables).
- Incorporate foods with protein (e.g., eggs, white meat, beans, milk, cheese, yogurt, and lean beef) into your loved one's diet.
- Keep healthy snacks available for when your loved one wants to eat.
- Encourage her to drink plenty of water (try for 8 glasses per day).

Talk with your loved one's cancer care provider if she is having difficulty eating or if you are concerned about the quality of her diet. They can give you nutrition tips and/or arrange for you to meet with a dietician.



Medicines

Several medicines are currently being studied to see if they help with cancer-related fatigue. Medicines are not a sole source of treatment for fatigue and if used, should be accompanied by exercise, sleep, and other strategies mentioned here. Together, you, your loved one, and her cancer care provider can decide if medicines might help with fatigue. Medicines that have been shown to have some effect for cancer-related fatigue include psychostimulants and other stimulants such as dextroamphetamine, as well as donepezil, a medicine used in patients with Alzheimer's disease.

Complementary and Integrated Therapies

Certain therapies are called "complementary and integrated" therapies because usually these are used alongside and/or with the more standard medical care you receive. In recent research studies, several of these therapies are proving useful in reducing sleep problems, but more research is needed.



The one good thing about my fatigue is I've learned to say 'no' to people now, where in the past, I always felt guilty not to help someone. Most people have cut me some slack. I also think fatigue has helped me prioritize what's really important in life. That's not so bad either. As Erma Bombeck would have said, 'Use your good dishes, burn your nice candles, enjoy friends and family and don't worry about dust and unimportant things.'



QUICK REFERENCE

Below is a recap of the general strategies that can help you as a caregiver manage your loved one's fatigue, sleep difficulties, and energy levels. Check those that you would like to try with your loved one. You can use this page as a quick reference.

- Determine what's causing the fatigue. Rate and track the fatigue. (Page 6:6)
- Get physical activity, such as walking. (Page 6:7)
- Practice energy conservation — the 4 P's. (Page 6:8)
- Practice energy restoration. (Page 6:8)
- Get rest and relaxation. (Page 6:9)
- Control pain and address emotional distress. (Page 6:10)
- Focus on nutrition. (Page 6:10)
- Talk to health care providers about medicines. (Page 6:11)

YOUR GOALS & STRATEGIES

What strategies make the most sense to you? How can you and your family use those strategies in your own life?

Create a Plan:

Think about specific goals you want to accomplish. Just tackle one or two goals at a time.

My goal is to _____ (what do you hope will happen) **by** _____ (timeframe) **so that** _____ (why it's important).

What specific strategies will you use to reach your goal? Think about the very next steps you can take to get started.
