



Caring for the
Caregiver:

Maintaining
Your Health
as a Caregiver

This guide will help you to:

- Feel more comfortable in addressing your own needs, emotions, and feelings.
- Understand how taking care of your own physical health and emotional well-being can benefit both you and your loved one.
- Develop powerful strategies to help you along the caregiving journey.

You have two hands,
one for helping yourself,
the other for helping
others.

—Audrey Hepburn

Caring for a Loved One with Cancer is Often Rewarding.

Fulfilling the critically important role of caregiver to a spouse, family member or friend can lead to feelings of accomplishment and personal growth. It may contribute to finding greater meaning or a greater sense of purpose in daily life. Caregiving can even have a positive effect on relationships, in which caregivers find themselves growing closer to their loved ones and family.

At the same time, it can be easy for caregivers to forget about their own personal health needs. That may lead to feeling a low overall sense of well-being.

Caregivers have talked about feeling overwhelmed and experiencing feelings of frustration, sadness, worry, or even guilt. They may give up their exercise routines, postpone their own doctor visits, or even stop participating in a hobby or social group. Many times they may feel exhausted and have problems with memory, sleeping, and thinking clearly.

It's common for caregivers to face many of their own physical and emotional challenges. But the key thing to remember is, *you are not alone!*

You can help your loved one by taking care of yourself.

Finding ways to maintain your own health and sense of well-being is critical to being a good caregiver. Because physical and emotional health are interconnected, it's important to pay attention to both. Taking time to address both your physical and emotional health will help you feel stronger and cope better as you care for your loved one.



How do Caregivers Describe Their Physical and Emotional Health?

Caregiving at times may feel like a whirlwind of feelings, both positive and negative. It is very common for caregivers to feel many different emotions and also undergo changes to their physical health. These are common words caregivers use to describe their emotional and physical state.

What about you?

Circle words that speak to you the most and write in anything else that describes how you're feeling.

**Anxiety, worry,
and fear**

Guilty

Exercising less

**More headaches,
aches and pains**

**Isolated
and alone**

**Proud of my
abilities to help
my loved one**

**Using
more tobacco
and/or alcohol**

**Exhausted and
always tired**

**Aware of my
strengths**

**Important
and valued**

**Trouble concentrating,
problem-solving, and
remembering things**

**Depressed,
sad**

**Feeling like
I know what matters
the most**

**Poor sleeping
and eating habits**



“

I think it would help to reduce stress if I could be involved in physical activities, such as exercising at the gym.

”

What Causes Physical and Emotional Health Problems for Caregivers?

As a caregiver, you are faced with many challenges: supporting your loved one through the side effects of gynecological cancer and its treatment, worries about the future for your loved one and yourself, and taking on more responsibilities as your loved one adjusts to life with cancer. You may also be juggling work, family, or your own health problems. Here are some things you may find yourself dealing with:

Stress, Anxiety, and Depression

Cancer caregiving is often complicated and demanding. Finding the time and energy to manage your household as well as your loved one’s appointments and treatments can be stressful and exhausting. This can lead to anxiety and depression for many caregivers.

Your Loved One’s Symptoms and Emotions

It is hard to watch a loved one face the challenges of cancer. Her situation can also affect your physical and emotional well-being. Changes in your loved one’s physical abilities and the need for you to provide direct, hands-on care can take its toll on you physically.

Taking On New Roles

As a caregiver, you may find yourself taking on new roles in your family and performing new tasks. Often, this is in addition to the jobs and activities you already do within your family. Many caregivers are responsible for making treatment and health decisions for their loved one.

No Time for Yourself

Caregivers often say that they don't have time for themselves. They may give up activities that offer social support and improved quality of life, such as hobbies and religious or social groups. It can seem difficult to find the time to join support groups or follow up on advice to help cope with feelings and your own needs.

Not Getting Enough Physical Activity

Balancing the demands of caregiving, work, and family, coupled with feelings of anxiety, fatigue, and depression, can all get in the way of exercise. Caregivers often say that they lack the time and energy to exercise.

While caregiving may be physically demanding, caregivers often find that they are actually less physically active than they were before their loved one's diagnosis.

Changes in Diet and Sleep

Diet and sleep are critical to health. Caregivers may feel they don't have the time and energy or the financial resources to prepare healthy meals.

They may have trouble falling asleep, wake too often, or wake too early. If your loved one is not sleeping well, it can be difficult for you to sleep. Feelings of stress, worry, and depression can impact sleep as well. In turn, problems with sleep can affect your memory function, resistance to infections, and overall well-being, making it harder to care for your loved one.

Not Getting Regular Medical Care

Caregivers often postpone their own medical and dental appointments. They set their own needs aside and are less likely to seek preventive care, fill their prescriptions, and see their doctor. It may feel like there isn't enough time or financial resources to follow up with their own health care needs.

Financial Hardship

Financial difficulties can negatively affect your health as a caregiver. Your loved one may be unable to work, or you may have to cut back at work, take extra time off, or quit a job. At the same time, insurance and medical coverage is often complicated and stressful to manage. The costs of co-payments, medicines, and hospital stays can lead to serious financial and emotional strain.

I need to find some down-time this weekend to restore myself a bit... mow the lawn, work in the garden, watch/listen to a Pirates game, so that I will have more energy to help me manage the things my wife is going through.

YOUR THOUGHTS

In what ways have you been affected physically and emotionally as a caregiver?

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.

Managing Your Physical and Emotional Health

Caregiving is hard work, but there are many things you can do that will help you feel better and prevent more problems down the road.

Here you can explore different types of strategies to manage your health. Pick those that you think may work for you and help you overcome your biggest barriers.

Bear in mind, it's not selfish to focus on your health needs—in fact, it's an important part of the caregiver's job. How can you help your loved one if you become ill? Improving your emotional and physical health will give you the strength you need to be an effective caregiver!

Check in with Yourself

Accept How You Feel. Start by accepting that feelings like anger, guilt, and frustration are common feelings for caregivers. It's important to recognize your own fears and concerns.

Take Stock of Your Situation. Ask yourself these questions:

- Do I have the tools I need to provide the best care, like knowledge, time, finances, and other support?
- Am I able to juggle the demands of caregiving with my usually day-to-day activities?
- Am I taking care of myself physically and emotionally?
- Do I have someone to talk to about these things?

Know the Signs and Symptoms of Depression and Anxiety. Every so often, ask yourself how you are feeling and coping. Watch for the signs of stress, anxiety, and depression. If you have these signs, call your HCP and ask for an appointment.

You can evaluate yourself for depression and anxiety. Visit: www.mentalhealthamerica.net/mental-health-screen



Helpful Tip:

Sometimes it's helpful to ask yourself, *"If one of my friends was in my situation, what advice would I give?"*



Talk with your HCP if you have any of these symptoms.

Signs of anxiety and/or depression:

- Worry 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



Helpful Tip:

Use websites and apps designed to help caregivers.

Visit:

www.CaringBridge.org to set up your own community and coordinate help and support from your friends and family.

Get Help from Others

Talk It Out. Having people to talk with about personal feelings, problems, and concerns—and even just “venting”—is key. Talk with those you can trust—a good friend, a pastor or spiritual leader, members of a support group, or a professional counselor or therapist.

Support groups for cancer caregivers (in-person or online) can be helpful. Talking with others who are going through a similar experience may help you feel less alone.

Seek and Accept Help and Support. *It's okay to ask for help!* Asking for help is a way to free up time, restore needed energy, and reduce your level of stress and worry.

If people offer to help, take them up on the offer. Don't be afraid to reach out to those around you. Build a community of support with family, friends, neighbors, co-workers, faith communities, or club members. Remember, there is strength in numbers! Your family and friends will want to be there to support you. Let them know what would be most helpful for you and your loved one.

Spirituality. Spirituality can provide comfort to many caregivers. For some, it may come with the practice of a religion or faith tradition. For others, it may be related to nature, art and music. Talking with a spiritual leader can help many caregivers deal with the stresses of disease and the demands of caregiving.



Respite Care

Many caregivers find it helps to have some time for themselves. This may require someone else taking over some of your responsibilities for a period of time. This is called *Respite Care*.

Respite care can be informal (friends or family) or formal (paid). It could be for an hour or two while you run errands or get some needed rest. Or, it could be for days at a time, when you leave town for some time off or attend a special event. Here are some tips for organizing respite care:

- **Schedule breaks** away from caregiving demands.
- **Take guilt-free time off.** Think about how this will restore your "caregiving batteries." Try to take some time every day to do something for yourself.
- **Look into respite programs.** Ask your gynecologic oncology team about respite services they would recommend.

Definition:

Respite Care

A temporary break for caregivers. A time to restore your "caregiving batteries."

Learn more at archrespite.org
(National Respite Network and Resource Center)

Seek Professional Help

If you are experiencing anxiety or depression that is interfering with your life, you should seek professional help. Consider talking with someone trained to provide counseling and other therapies for anxiety and depression. This might include a psychiatrist, a clinical psychologist, or a clinical social worker who can offer treatments, such as:

- Counseling and supportive expressive therapy
- Cognitive behavioral therapy (CBT)
- Medicine for anxiety and depression

Sometimes, it's possible to feel so overwhelmed that you have an impulse to hurt yourself or someone else. If you do not feel safe, the first thing to do is to notify your health care team or call 911. You will be supported to find immediate help. Or call the National Suicide Prevention Lifeline at 800-273-8255.



Talk with your HCP or oncology team for a referral.

They can also help you find resources, answer questions, and provide support. Ask about other referrals to people that can help you with:

- Financial services
- Spiritual care
- Chore services

Manage Your Emotions

There are numerous techniques to manage feeling stress, sadness, anger, frustration, and guilt. For most people it's useful to use more than one strategy at a time. There is no "one-size-fits-all" approach.

Relaxation. You may feel too busy to take time to relax. Here are some quick tips to help you unwind:

- Make a list of things that help you feel more relaxed and keep it handy. Try to find time daily to relax.



Helpful Tip:

Make a “Worry List”

Earlier in the day jot down your worries, then set the list aside. Before you go to bed, reassure yourself that your worries are written down and set aside. Tell yourself you have time to worry tomorrow.

- Try out different techniques: meditation, yoga, progressive muscle relaxation, guided imagery.
- Take advantage of times when your loved one has appointments or treatments.

Positive Thinking. Finding positive ways to think about your experiences in caregiving can make it easier to cope with the hard work, worry, and fear. Here are some things you might think about:

- **Don’t sweat the “small stuff.”** Figure out what matters most to you and your loved one.
- **Look for “silver linings.”** Accept that you can’t solve every problem and look for the good things that have resulted from a very tough situation. At bedtime, reflect on the positive in the day.
- **Try positive self-talk.** Acknowledge what you have done well and ways you have made a difference.
- **Write in a journal.** A journal can be helpful for those who have a hard time sharing their feelings. Research shows that expressing deep thoughts through writing can help with depressive symptoms.
- **Reflect.** Write down ways you have grown, things you have learned, and special moments that have happened. When you are sad or distressed, these things can bring you comfort.

Set Limits. Reduce your stress by limiting your availability for activities like gatherings, clubs and groups, or volunteer work. Use these quick tips:

- Plan for shorter amounts of time.
- Focus on the meaning, worry less about the details.
- Ask someone else to host an event you usually have in your home.
- Let your family and friends know your new limits.

Laugh. Humor and laughter can have physical and emotional benefits. Humor increases relaxation, reduces stress, and improves feelings of well-being.

- Allow yourself to laugh and find ways to bring laughter into your life. Share humor and laughter with your loved one, if possible.
- Don’t feel guilty about laughing or about feeling times of happiness.
- Sources of humor can include: TV shows, books, movies, funny animal YouTube videos, puns and jokes, improv comedy, or humor or laughter therapy workshops in your community.

I keep a notebook by the TV and when I sit down, I write in it....I continue to add to my list of ‘positives’...I review the list now and then and think about what I listed.



Practice Healthy Lifestyle Habits

Caregivers often find it difficult to carry out their own preventive health activities and get routine check-ups. Plan ahead. *Make this a priority, to help both yourself and your loved one.*

Exercise and Stay Active. Physical activity is one of the best ways to reduce stress and improve sleep, depression, and anxiety. Fitness centers offer not just exercise, but also a needed break and a chance to socialize. But you don't always have to go to a gym to stay active:

- Take a walk while waiting at appointments.
- Work around the house or in the garden/yard.
- Work up to exercising 30 minutes, 3 times per week.

Keep Your Heart Strong. Do what you can to keep a healthy heart: get regular blood pressure and cholesterol screenings, take prescribed medications, eat a healthy diet and control your weight, exercise regularly, manage your stress levels, and quit smoking.

Be Good to Your Back. Sometimes caregiving can be very physical, involving personal care, lifting, moving, and performing physical tasks around the home. Here are some tips to prevent back injuries:

- Learn the best way to do tasks like helping your loved one get up and around.
- Talk to your HCP about back problems and ask for a referral to a Physical Therapist.
- Take a class on caring for your back. Often these types of classes are covered with insurance.

Eat a Healthy Diet. Eat a nutritious diet rich in fruits, vegetables, and whole grains. Avoid saturated fats and added sugars to reduce the risks of many chronic conditions, including heart disease and diabetes.

If cooking is becoming difficult, you and your loved one may qualify for home-delivered meal services such as Meals on Wheels.

Manage Your Sleep. Sleep loss can lead to physical and emotional health issues, but there are many strategies to help you get a better night's sleep.

- Keep a sleep diary
- Develop good sleep hygiene and pre-bedtime routines, including relaxation techniques
- Get regular physical activity during the day



Learn More

Go to “**Maintaining a Healthy Lifestyle as a Caregiver**” (on page 2:2) for in-depth strategies on exercise and physical activity, nutrition and meal preparation, sleep, and self-care as a caregiver.



How to Talk with Others About Managing Your Health as a Caregiver

Your family and friends can help in many ways by being there to talk to, relieving you of some of your tasks and responsibilities, and providing you time for respite. Here are some ways they might help:

- Make healthy meals for you to be frozen and saved.
- Get some exercise or go for a walk with you.
- Help arrange a family meeting.
- Join a support group with you.

Talk with your HCP about your health concerns as a caregiver:

- Ask about diet and nutrition and exercise programs.
- Ask for information about support groups, counselors, nutritionists, and social workers.
- Identify health problems and report them early.
- Ask about preventative services (exams, screenings, vaccinations).

QUICK REFERENCE

Below is a recap of the general strategies that can help you maintain your emotional and physical health. Check those that resonate the most with you. You can use this page as a quick reference.

- Check in with yourself. Evaluate how you feel, ask yourself questions to get prepared. (Page 2:7)
- Get help from others. Reach out to those around you and talk with those you can trust, including friends and family, support groups, or spiritual leaders. (Page 2:8)
- Schedule respite care and take time for yourself. (Page 2:9)
- Get help from your HCP for anxiety and depression. (Page 2:9)
- Manage your emotions through relaxation techniques, positive thinking, laughter, and setting limits. (Page 2:10)
- Practice healthy lifestyle habits: exercise and physical activity, diet and nutrition, sleep hygiene, and medical care. (Page 2:11)



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.



The information in this guide is based on research funded by the National Institutes of Nursing Research to Dr. Heidi Donovan and Dr. Paula Sherwood (NIH/NINR NR010735 and NR013170).

This guide was written/adapted by:

Janet Arida, PhD, RN, MSW; Education And Outreach Coordinator; Child Grief Specialist · HIGHMARK CARING PLACE

Danielle Commisso, Pittsburgh-based freelance writer

Heidi Donovan, PhD, RN; Professor of Nursing and Medicine; Co-Director, National Center on Family Support, University of Pittsburgh;
Director, GynOnc Family CARE Center, Magee-Womens Hospital of UPMC

Jane Dudley, Assistant Creative Director, University of Pittsburgh

Mary Roberge, BSN, GynOnc Family CARE Center Coordinator, Magee-Womens Hospital of UPMC

The production of this guide was made possible by a generous donation from Clovis Oncology.