

How to Support a Partner

The role of a partner and caregiver in a cancer diagnosis

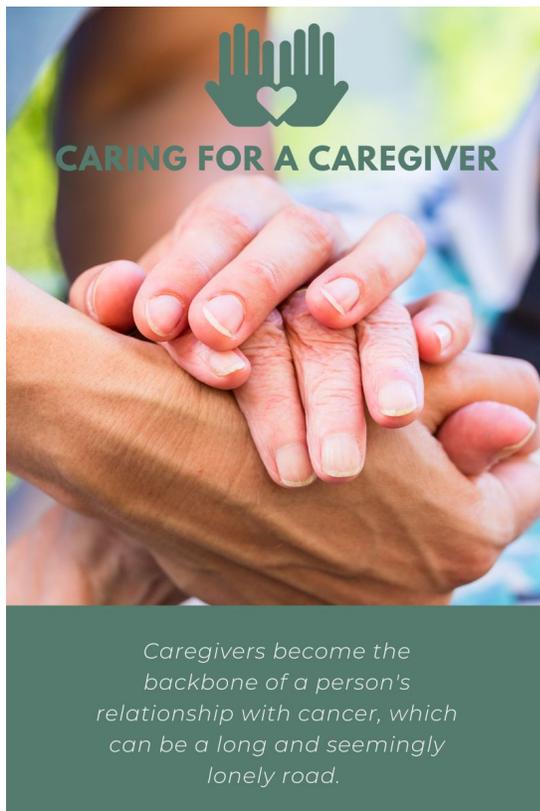
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Support and the Caregiver

Caring for a Caregiver

When test reports come in, and the building anticipation confirms the worst fears with a diagnosis of cancer, it certainly affects the individual the most. However, its ripples are far reaching; we share it with our parents, family, partners, children or friends, and almost anyone that we can rely on for support. These individuals become the backbone of one's journey to fighting the battle with cancer, which can be a long and seemingly lonely road. The presence of a strong support system can make it feel easier. In this journey, the "caregivers", our loved ones who are supporting us, often go unnoticed in their daily struggle by the doctors, relatives, and even themselves.

To help combat that sense of caregiver fatigue, we are sharing some useful strategies to support a loved one, and in the process, also understand the role and challenges of a caregiver.



Who is a Caregiver?

If you are assisting someone you love during cancer care, you are a caregiver.

It feels like something natural to do—taking care of someone you love. However, “taking care” comes in different forms and versions during different stages of the journey.

Caregivers can be family members, friends, or anyone who cares for a person with an ailment. Since every situation is different, caregiving will also look different for every case, and there isn't one way that works best. For example, caregiving may include:

- Helping with personal needs and household chores
- Managing a person's finances
- Arranging for outside services

- Visiting regularly
- Planning doctor's visits and ensuring adherence to treatment
- Managing emotional and psychological distress by listening, talking, and supporting
- Being the contact person to keep others updated

The Impact of Diagnosis - A Partner's Perspective

The thought of cancer is frightening, and in the time after diagnosis of a loved one, you may experience a range of different feelings. Some common reactions include:

- Feeling anxious and scared, or perhaps upset or emotional
- Feelings of shock and numbness
- Feeling confused, especially when trying to understand complex medical information
- Feeling overwhelmed with responsibilities about helping in the decision-making of medical treatments
- Feelings of helplessness and frustration in response to seeing their partner undergo many medical tests and procedures
- Feeling angry that their loved one got cancer, or wishing that the cancer had been found earlier

The above reactions are extremely normal and expected upon hearing the diagnosis. It becomes important to validate our own feelings and approach them without judgment. However, it is also essential to consider the possible challenges caregivers might encounter. Awareness about such challenges helps better prepare and hence mitigate the stress associated with it.

Challenges Faced by Caregivers :

- Emotionally processing the initial diagnosis or recurrence
- Managing the practical and emotional aspects of patient care
- Facing an uncertain future
- Encountering symptom-related suffering

The Psychological Consequences of Caregiving

The experience of caregiving varies by each caregiver, hence its consequences also fall under a spectrum. Some caregivers report positive outcomes, while others report negative experiences, and some find themselves in a combination. There is no singular way to experience this process.

Positive Outcomes of Caregiving:

Many caregivers are able to find the silver lining in this experience and the following themes have been found to be the most common:

- Greater appreciation of life
- Clarification of life priorities.
- Increased faith
- Increased empathy for others
- Better health habits

- Positive self-view
- Reprioritization
- Enhanced relationship with the care-receiver
- Increased self efficacy and the feeling of being rewarded
- A sense of personal growth and a perception of personal satisfaction

Negative Consequences of Caregiving:

On the other end of the spectrum lie the “negative consequences”. It is imperative to understand that the term “negative” does not mean something that shouldn’t be experienced, or should be a cause of shame. Rather, caregiving creates demands that may exceed one’s resources and ultimately cause negative psychological consequences. The aim is to have insight into expected negative outcomes to assist in finding the right source of help.

- Anxiety
- Depression
- PTSD
- Health anxiety
- A decline in caregiver quality of life

Fear, hopelessness, guilt, confusion, doubt, anger, and helplessness can take a toll on both the person with cancer and the caregiver. While the focus tends to be on the patient, all of this will affect the caregiver’s physical and mental health, too.

Caregivers can also come to a point where they feel that they’ve failed in some way, which is a natural and expected feeling. However, this acute feeling can be managed at an early stage and improve the overall quality of life.

Ways to Cope with Consequences of Caregiving

In this section, we discuss possible measures we can take to support ourselves with the struggles of being a caregiver.

Taking a Break/ Finding the “Me Time”

Caregiving feels like a full-time occupation, but it does not have to be. Caring for one’s self actually equips one to perform the role better.

Most caregivers might hesitate to take a break from their caregiving responsibilities, as they feel guilt for stepping away, even temporarily. However, denying your physical and mental health needs for an extended time will upend one’s identity.

Try to get out of the house and be on your own daily, even if just for a few minutes. This could be as simple as taking a short walk or shopping for food. Some caregivers also work full-time jobs while taking care of their loved one. While this can be a needed break, it can also add stress to the situation. Any activity that also allows you the independence to be just you, no matter how small, may help center yourself and prevent burnout.

Know Your Limitations- You Cannot Pour from an Empty Jug

Caregivers are also their own individuals who have their own set of needs, wants, and desires. They also have a set amount of resources.

We act as caregivers for people who are often close to us and hence overburden ourselves with responsibilities. Sometimes, we are riddled with guilt and fears that we are not doing our best.

A person can only give so much. After that, you need to replenish. It is important to remember that the inability to give at the moment does not translate to failure.

Drawing boundaries is healthy and asking for help is healthy too. Setting realistic limits on what you can do becomes essential. For instance, if you have a back injury, and your loved one is too big for you to lift, you may be able to help them roll over in bed, but don't try to lift them alone or catch them if they fall. You may end up seriously injured and become unable to help anyone. This is where expert help is needed; home care nurses or physical therapists can show you how to work safely. They can also help you get special equipment if needed. Your own health and safety must come first if you want to keep helping your loved one.

Finding Support for Yourself

The most striking thing about support is that it helps you to “share”. Share the burden, the responsibilities, the toil. It does not promise to take it away but definitely helps unburden by sharing it. Some possibilities can be:

1. Family and Relatives - Traditionally support is found from family, relatives, and friends which provide a safe space to feel the various emotions that erupt from the journey of treatment for cancer.
2. Support Groups - Some of us might find more solace in sharing and seeking support from individuals who find themselves in a similar situation as yourself, which makes you feel truly understood. Talking with others who are in situations similar to your own can help ease loneliness. One also gets useful ideas from others that might be helpful. GRACE has an active forum for those looking for support, and it can be found [here](#).
3. One on One Counseling- Another option is speaking to a professional who is trained to assist, support, and provide care in the situation to increase self efficacy.

Be Prepared for Some People Not to Help

When someone has a serious illness such as cancer, friends and family often reach out to help. Sometimes people you *don't* know very well also want to give you a hand. However, it's important to realize that there are others who may not be able or willing to help you. You may wonder why someone wouldn't offer to help you or your family when you're dealing with so much. Some common reasons are:

- Coping with their own problems
- Not having the time
- Fear of cancer or having already had a bad experience with cancer; not wanting to get involved and feel pain all over again
- Believing it's best to keep a distance when people are struggling
- Not realizing how hard things really are for you, or not understanding that you need help unless you ask them for it directly
- Feeling awkward because they don't know how to show they care
- Cultural differences in appropriateness of offering care

If someone isn't giving you the help you need, you may want to talk to them about your expectations, particularly if the relationship is an integral part of your life. They may very well be open to discussing the issue and allow you to see their point of view. Or, you can choose to let it go. No matter your choice, dealing with the issue can prevent resentment and stress from building up.

Self-Compassion

Feelings are not inherently “good” or “bad”; they simply exist, and need to be understood. The first step to understanding your feelings is to know that they're normal, and, more importantly, valid.

Some feelings that may come and go are:

- **Sadness.** It's okay to feel sad. However, if it lasts for more than 2 weeks, and it keeps you from doing what you need to do, talk to your doctor.
- **Anger.** You may be angry at yourself or family members. You may be angry at the person you're caring for. Know that anger often comes from fear, panic, or stress. Try to look at what is beneath the anger.
- **Grief.** You may be feeling a loss of what you value most. This may be your loved one's health, or it may be the loss of the day-to-day life you had before the cancer was found. Let yourself grieve these losses.
- **Guilt.** Feeling guilty is common, too. You may think you aren't helping enough, or you may feel guilty that you are healthy.
- **Loneliness.** You can feel lonely, even with lots of people around you. You may feel that no one understands your problems. You may also be spending less time with others.

Experiencing these feelings just means that you are human, and you need the same attention and care that you as a caregiver extend to others around you.

Caring for Your Body

You may feel too busy or worried about your loved one to think about your own health. Yet it's common for caregivers to have sleep problems, headaches, and anxiety, along with other physical changes.

Did you have health problems before you became a caregiver? If so, now it's even more important to take care of yourself. Also, adding extra stressors to your life can cause new health problems. Be sure to tell your doctor if you notice any new changes in your body. Keep up with your own health needs.

Try to:

- Go to all your checkups
- Take your medicines
- Eat healthy meals
- Get enough rest
- Exercise
- Make time to relax

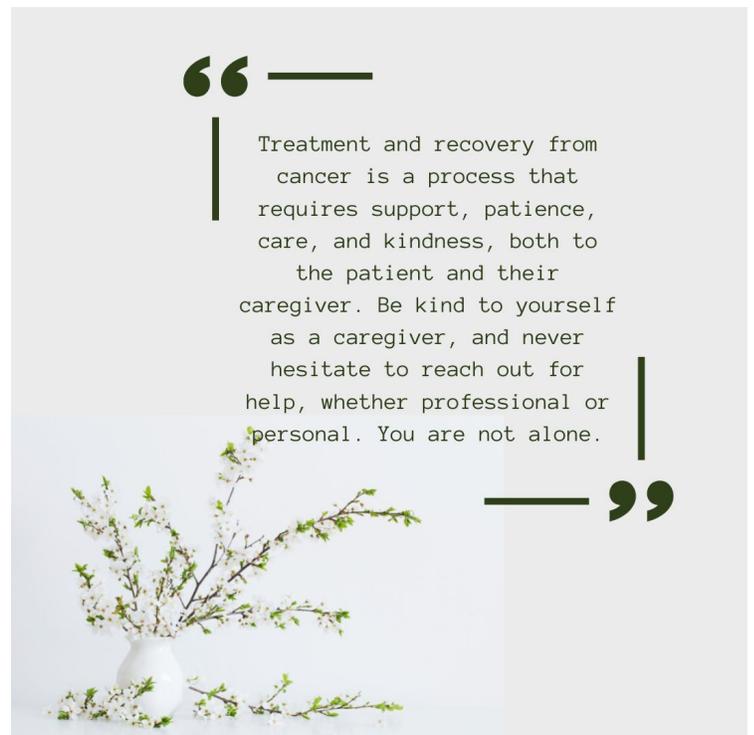
Finding Meaning During Cancer

Cancer causes many caregivers to look at life in new ways.

They think about the purpose of life, and often focus on what they value most. You and your loved one may question why cancer has come into your lives. You may long for things to be like they were before the disease. You may also see good things that come out of it, such as it bringing you closer. It's normal to see illness in both good and bad ways.

Talking With Your Partner

A lot of fears and insecurities that arise after the diagnosis may be centered around the challenges associated with decision making and the well-being of our partner suffering from cancer. Sometimes having an honest and empathetic conversation can help appease fears. Some suggestions are:



- Talk about how each of you are feeling
- Share how you are each coping
- Look at things that are causing you both stress
- Talk about choices you can make together
- Try to be grateful for each other
- Make time to focus on things besides cancer

Treatment and recovery from cancer is a process that requires support, patience, care, and kindness, both to the patient and their caregiver. Be kind to yourself as a caregiver, and never hesitate to reach out for help, whether professional or personal. You are not alone.

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Sharika received her MPhil in Clinical Psychology at Dr. Ram Manohar Lohia Hospital (PGIMER) and Masters in Clinical Counseling and Applied Psychology at Delhi University. We thank Sharika for volunteering and helping the GRACE community!

<https://cancergrace.org/post/how-support-partner>