FRANKLY SPEAKING ABOUT CANCER
A PROGRAM OF THE CANCER SUPPORT COMMUNITY

10 TIPS FOR NAVIGATING LOGISTICS AS A CAREGIVER

Cancer impacts not only the person with the diagnosis, but also everyone who cares about them. This includes those who take on the caregiver role. A caregiver, or care partner, is someone who helps take care of and supports a loved one with a health concern, like cancer. This support can take many forms, and the kind of help your loved one needs may change from day to day. Being flexible and ready to adapt is an important part of caregiving. Caregivers can help in physical, emotional, practical, and spiritual ways.

Physical needs can include:

- Providing a safe living space
- Bathing
- Dressing
- Feeding
- Turning
- Helping with medications

Emotional needs can include:

- Providing comfort, support, and companionship
- Helping to stay socially connected with friends and family
- Supporting their loved one's participation in hobbies and activities that improve their quality of life

Practical needs can include:

- Coordinating medical appointments, transportation, and communication with their healthcare team
- Managing money, bills, and health insurance paperwork
- Cooking
- Cleaning
- Completing yardwork and taking care of other dependents/pets

Spiritual care needs can include:

- Respecting beliefs, traditions, and values
- Supporting prayers
- Giving space for life review, legacy planning, and reflection

Caring for someone with cancer can be both meaningful and overwhelming. It is normal to feel uncertain, unprepared, or even emotionally drained. You are not alone. **Your care and support matter at every stage of the cancer experience.**

This tip sheet provides caregivers with 10 practical ways to support yourself while caring for your loved one. Taking care of your own well-being is not only necessary, it helps you be the best support you can be.

For more resources and support for caregivers, visit **www.CancerSupportCommunity.org/Caregivers**.

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

1 LEARN ABOUT YOUR LOVED ONE'S CANCER

Learning more about your loved one's cancer can help you feel more in control and prepared during a challenging time. Ask the healthcare team for information and resources. Focus on understanding key details, such as the type and stage of the cancer, treatment options including any clinical trials, and possible side effects. Your loved one's healthcare team is a great source of information. Knowing and understanding what to expect can help build your caregiver confidence, which helps your loved one and you. Make notes of your questions or anything you do not understand to ask the healthcare team. You may also serve as an advocate for your loved one.

2 GET TO KNOW THE HEALTHCARE TEAM

Whether you start caregiving right after a diagnosis, or step in later, it is helpful know who is part of your loved one's healthcare team. No matter when or how you begin, you are an important and valuable part of your loved one's team!

- Ask what each person does and how they can help.
- Be sure to get the best phone number to call for questions during the day. Find out if there is a different number to use after hours.
- Every question is important, so do not be afraid to ask. The healthcare team is there to support you both.

If a patient portal is available, find out how to use it for non-urgent questions or updates. Knowing who to turn to can bring peace of mind and make you feel more prepared as you navigate this experience.

3 LEARN ABOUT YOUR LOVED ONE'S SIDE EFFECTS

It is important to know what side effects might come up during or after your loved one's treatment. The healthcare team should explain what to expect, but do not hesitate to ask questions, especially about how you can help manage those side effects at home.

Each person's experience with cancer is different. Depending on the diagnosis and treatment plan, other specialists can help. If your loved one is struggling with symptoms like pain, ask if the palliative care team can offer support. If you notice any new or worsening side effects, let the healthcare team know right away. Learning about possible side effects before they happen can help you feel more prepared and confident in supporting your loved one when challenges arise.

To learn more about managing side effects, visit **www.CancerSupportCommunity.org/Managing-Side-Effects**.





4

LEARN ABOUT SUPPORTIVE CARE OPTIONS

Supportive care can make a big difference for both the person with cancer and the caregiver. It includes services that help manage symptoms, reduce stress, and improve quality of life. Supportive care looks different for everyone, depending on their needs and stage of treatment. There are different types of supportive care. These can include:

Respite care gives caregivers a temporary break so they can rest and take time for themselves away from caregiving duties. Whether it is for a few hours or a few days, respite care can help prevent burnout and give you time to recharge. Respite care can take place at a care center or at home. This might look like a home health aide stepping in for a few hours while you attend a medical appointment or take time to rest. Talk with the healthcare team to see what respite care options are available in your area.

Palliative care focuses on symptom management during and after treatment. It supports physical, emotional, social, and spiritual needs while managing symptoms, pain, and other side effects. It can be provided at any time. Palliative care is different from hospice care.

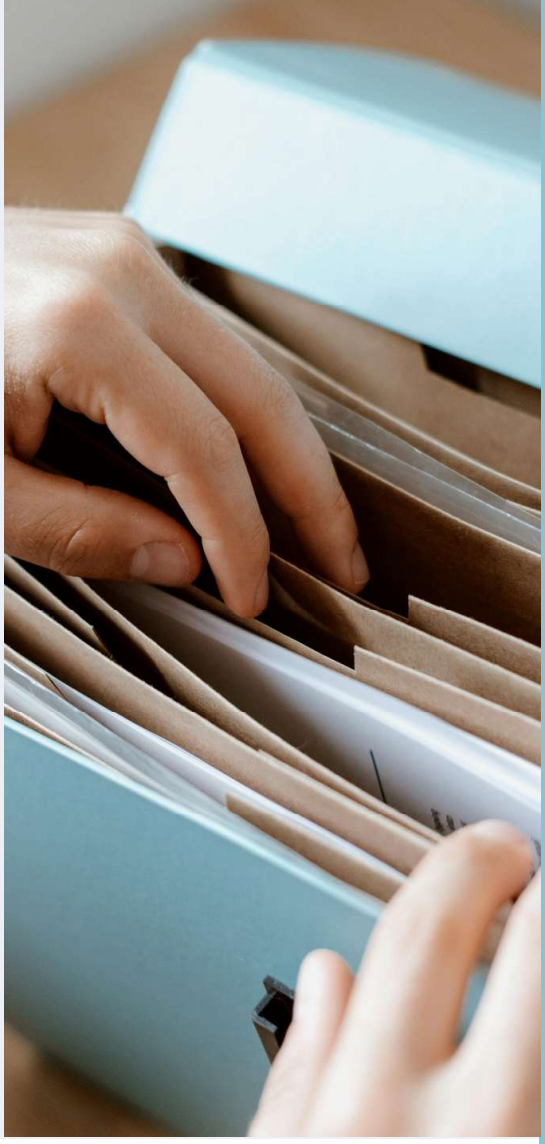
Hospice care is for when treatment is no longer working or when the focus shifts from curing the disease to maximizing comfort. It supports both the person with cancer and their loved ones through physical care, pain management, and emotional or spiritual support. The hospice team may include doctors, nurses, social workers, home health aides, and spiritual leaders. Hospice can be provided at home or in a facility like a nursing home. The hospice team is available 24/7. Hospice also provides bereavement support after the loss of a loved one.

Supportive care is about improving quality of life for both you and your loved one. To learn more about supportive care options, check out CSC's resource, **Frankly Speaking About Cancer: Understanding Supportive Care**.

5 KEEP IMPORTANT DOCUMENTS IN ONE PLACE

It is a good idea to keep all of your loved one's important information together. This can include medical records, insurance cards, notes from appointments, and a list of their medications. You can keep the contact information for the healthcare team in the same spot. Use a dedicated binder or notebook to help you stay organized. The healthcare center may have an app or patient portal that has information about upcoming appointments and medication history. Ask the healthcare team if this is something you can use to help stay organized.

Be sure to include health insurance documentation and contact information for the insurance provider. This can be important when managing claims, approvals, or billing questions. If your loved one is receiving disability or unemployment benefits, or has applied for them, keep all related documents in this folder as well. Try to always have these documents with you. **Having everything in one location can reduce stress and make it easier to respond quickly when information is needed.**





6 CREATE A CALENDAR TO HELP YOU STAY ON TRACK

Keeping track of appointments, treatments, and caregiving tasks can feel overwhelming. It may help to create a separate calendar just for your loved one's care. You can use paper or keep one on your phone or computer. Add doctors' visits, treatments, and anything else you need to coordinate. If others are helping with care, share the calendar so everyone knows the schedule. Set reminders or alerts to avoid missing important appointments. It is OK to update and adjust the calendar as needs change.



7 KNOW YOUR RIGHTS AT WORK

Balancing a job while caring for a loved one with cancer can be challenging. You may be able to take time off work to care for a loved one. The Family and Medical Leave Act (FMLA) allows up to 12 weeks away from your job and protects your job. It is usually not paid. You can take it all at one time or intermittently (a few days a week). Not all jobs or employees qualify for FMLA, so talk with your employer or human resources department about your options. Some workplaces also offer flexible hours, remote work, or employee assistance programs that can provide additional support. A social worker or financial navigator can help you with FMLA questions and paperwork.

8 NAVIGATING FINANCIAL NEEDS

Cancer care can be expensive, and there may be costs separate from treatment. You might face expenses for transportation to appointments, lodging near treatment centers, or other everyday needs. **You do not have to manage these challenges alone.** Ask a social worker or financial navigator if there are programs that can help. Many healthcare centers partner with local hotels and transportation services that offer free or low-cost options. Organizations like Cancer Support Community can also find ways to help with these costs. Do not hesitate to ask for help. Getting support with finances is an important part of caregiving.

Cancer Support Helpline
If you need help finding resources or want help getting information about cancer, call CSC's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m. - 8:00 p.m. ET and Friday 11:00 a.m. - 6:00 p.m. ET.

9

ASK FOR HELP AND BUILD YOUR SUPPORT NETWORK

It is OK to ask for and receive help. When others offer to help, it is common to feel overwhelmed or unsure of what to ask for in the moment. It can be helpful to create a list ahead of time that outlines the types of help you and your loved one might need —whether occasionally or on a regular basis. This way, when someone says, "Let me know if you need anything," you can give them a clear way to support you.

People who can help include:

- **Family, friends, and other loved ones: Share caregiver tasks and can give you breaks by:**
  - Helping with errands (such as the post office or dry cleaning)
  - Caring for dependent children and pets
  - Grocery shopping or other needs
  - Prepare or deliver meals
  - Getting to and from appointments
- **Licensed social workers and therapists: Help you cope with stress and the challenges of caregiving**
- **Private duty (paid) services: If financial resources are available, you can also pay professionals to help with caregiving tasks**

Having this list ready can ease the burden of decision-making when you are exhausted or overwhelmed. It also gives your support network a chance to contribute in meaningful, practical ways that truly make a difference.



Cancer Support Community MyLifeLine®

MyLifeLine® is an online community that allows you to make a list of things you need help with and who can help with each task. Family members, friends, and loved ones can be added so they can help. The needs could be providing meals, helping with transportation, or caring for children. To join, visit **www.MyLifeLine.org.**

10

TAKE CARE OF YOURSELF

When you are caring for someone else, it is easy to ignore your own health and well-being. **Your needs are just as important!** Caregiver stress and burnout are very real and common. Take time to care for yourself. What you need to feel supported may change over time, and that is OK. Make sure that you get the support, take breaks, and spend time doing activities you enjoy. Take care of your own health and well-being.

There are free services just for caregivers. Talking with a social worker is a great place to start to find support. Many organizations have in-person or virtual support groups and hotlines at no cost. Contact your local Cancer Support Community or Gilda's Club to see what is available.



RESOURCES

Caregiver Resources

Cancer Support Community
888-793-9355 | www.CancerSupportCommunity.org/Caregivers

National Alliance for Caregiving
202-918-1013 | www.Caregiving.org

This Is Living With Cancer
www.ThisIsLivingWithCancer.com

MyHealthcareFinances
www.MyHealthcareFinances.com

Caregiver Action Network
855-227-3640 | www.CaregiverAction.org

Family Caregiver Alliance
800-445-8106 | www.Caregiver.org

National Cancer Institute
800-422-6237 | www.Cancer.gov

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793- 9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. To order printed copies of this publication and others, visit **Orders.CancerSupportCommunity.org**

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. **www.CancerSupportCommunity.org/Find-Location-Near-You**

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**

MyLifeLine® — CSC's online community welcomes anyone impacted by cancer to easily connect with others. Create a personal network site and invite friends & family to follow your journey. Participate in our discussion forums to meet others who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Share your voice with federal and state policy makers on issues affecting cancer patients and survivors. Join our Grassroots Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Caregivers**.
For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org.**

Frankly Speaking About Cancer: Caregivers Program Partner:

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