What is a caregiver?

A caregiver is anyone who helps or supports a loved one who is dealing with a serious illness. A caregiver might be a relative, friend, neighbor, or coworker. They might live with the person, nearby, or far away. Support may be financial, physical, emotional, or spiritual.

Caring for someone with cancer is not easy. Even the most dedicated caregivers have tough days. There may be choices to make. When your loved one has a rare cancer, like Merkel cell carcinoma, it can be especially hard to find the information and resources to support them fully.

This fact sheet is designed for people who are caring for loved ones or others with basal cell carcinoma, squamous cell carcinoma, or Merkel cell carcinoma. Your experience will vary depending on the type and stage of the cancer. Some tips on this list may not apply to your situation now, or ever. Some may be relatable, even beyond cancer.

1. **Learn about the diagnosis.** By understanding the cancer, you can better support your loved one. Read or ask about treatment options, possible side effects, and expectations for recovery. Focus on trusted websites like those listed in this fact sheet.

2. **Support your loved one in finding the right treatment team.** Skin cancer is often treated by a dermatologist. Other specialists are involved as needed. If the procedure involves surgery to the face, the treatment team should include a doctor or surgeon who has experience restoring appearance. Look for a doctor who has experience treating non-melanoma skin cancers.
Encourage your loved one to go to a National Cancer Institute cancer center or university hospital. Ask about the full range of services and treatment options including clinical trials.

3. **Weigh the pros and cons of each treatment with your loved one.** Consider things like time, cost, where treatment will be given, possible side effects, and balancing your loved one’s goals for treatment with what’s available.

4. **Ask about financial assistance.** Some pharmaceutical companies, support organizations, and clinical trials offer co-pay support when asked. Your loved one may be eligible for other discounts, too. Always ask.

5. **Create a “to do” list with your loved one.** Include immediate and long-term needs. Decide what your loved one can do on their own, and what you or someone else can do.

6. **Recognize and respect the wishes, capabilities, and roles of everyone involved.** Each stage of care will require different levels of support, and roles will change over time. Openly talk about what you and others can reasonably provide, what your loved one can do, what outside organizations can help with, and what must adjust along the way.

7. **Organize a care-plan calendar.** Include who is doing what, and when. This can help reduce a patient’s stress and bring needed relief. MyLifeLine.org offers a way to keep track of tasks that everyone can help with.

8. **Set your own limits.** Offer help in reasonable ways. If you can’t help with something (which is fine), look for other ways to get your loved one the help they need.

9. **Gain permission to get copies of medical records when needed.** Legal “Power of Attorney” will allow you or someone else to help with follow-up care plans and future medical or financial needs.

10. **Tap into support services.** An oncology social worker or financial navigator can be very helpful for you. Look at websites from organizations like Cancer Support Community or CancerCare. Attending support groups with other cancer caregivers who understand what you’re going through can also be very helpful. To see if there is a local CSC or Gilda’s Club affiliate that offers a support group near you, visit www.CancerSupportCommunity.org/FindLocation.
11. **Take care of yourself.** When you take care of yourself, you can do a better job of helping others. If you need a “break,” ask about respite care. Respite care offers short-term, temporary relief for caregivers. It brings a professional caregiver to the patient’s home for intensive care and is available for short periods of time. The patient’s health care team and insurance company can tell you more about these services.

12. **Try to find humor and pleasure in life so you can enjoy special moments together.**

**OTHER TYPES OF CARE ASSISTANCE MAY BE AVAILABLE, DEPENDING ON YOUR LOVED ONE’S NEED OR STAGE OF ILLNESS:**

**Palliative care** offers help with symptom and side effect management. The focus is on improving quality of life. It is available at any stage of illness but can be most beneficial earlier in treatment.

**Hospice care** offers a full range of care to a person with cancer and their family within the last six months life. It can be offered in your home or in a hospice care setting.
NON-MELANOMA SKIN CANCER INFORMATION AND SUPPORT

American Cancer Society of Clinical Oncology · 888-282-2552 · www.asco.org
CancerCare · 800-813-4673 · www.CancerCare.org
National Institute of Health’s Clinical Trial Search · ClinicalTrials.gov
Skin Cancer Foundation · www.SkinCancer.org
Merkelcell.org · www.Merkelcell.org
American Academy of Dermatology Association · www.aad.org/public/diseases/skin-cancer/types
Patient Advocate Foundation · 800-532-5274 · www.Patient Advocate.org
National Cancer Institute · 800-422-6237 · www.cancer.gov
National Comprehensive Cancer Network · 215-690-0300 · www.nccn.org/patientresources/patient-resources/guidelines-for-patients

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-Fri 9am-9pm ET and Sat-Sun 9am–5pm 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. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda’s Clubs — With the help of 170 locations, CSC and Gilda’s Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

MyLifeLine — CSC’s private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

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

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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