

Understanding Supportive Care

CANCER CAREGIVERS

Helping the Helper

Frankly Speaking About Cancer



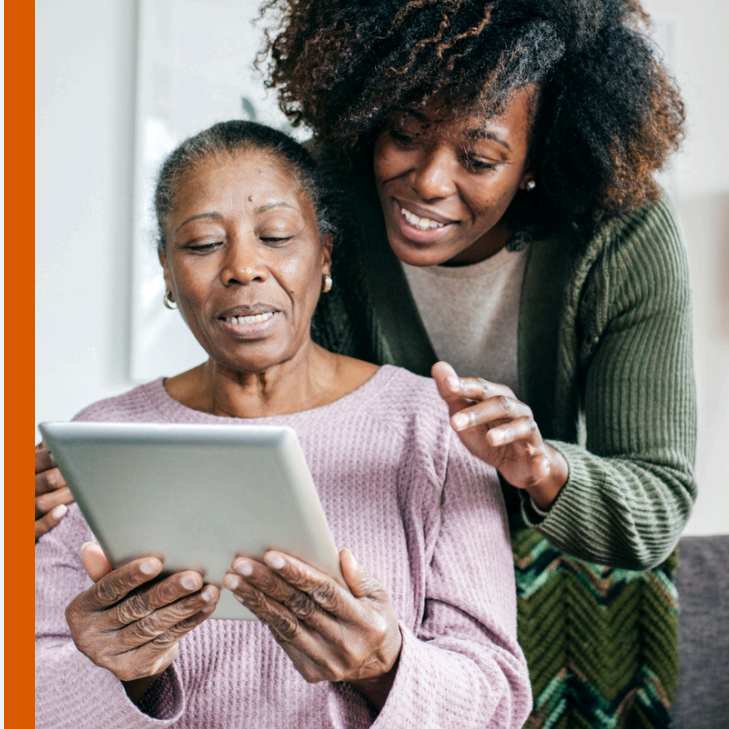
Caring for someone with cancer can be a rewarding experience. This role can also be overwhelming at times, with its fair share of challenges. As a caregiver, you may need to support someone else's physical, social, and emotional needs. You may also need to help with different treatment decisions.

When talking about cancer treatment, you may hear about "supportive care" options. Two of the most common options are palliative care and hospice care. Understanding the difference between these two can be confusing. They may be difficult to navigate as you deal with other caregiving tasks.

This fact sheet explains the difference between palliative care and hospice care. It talks about the different healthcare specialists that serve on each care team. It also talks about how to be active in the decision-making process. At the end of this piece, you will find several resources for support.

WHO ARE CAREGIVERS

In this fact sheet, the term caregiver describes anyone who provides or arranges help for a person with an illness or health concern. This type of help can be physical, emotional, spiritual, financial, or logistical. A cancer caregiver is anyone who provides support and informal care to someone diagnosed with cancer. The term “loved one” is used in this piece to describe the person diagnosed with cancer. This could be someone with whom you have any type of relationship and are assisting with their care needs.



WHAT IS PALLIATIVE CARE?

Palliative care is a type of supportive care. It aims to help patients, and their caregivers or care partners, maintain their best possible quality of life. This type of care is available to people of all ages impacted by a serious illness, like cancer. Palliative care is different from hospice care. It is available at any point in the cancer experience. It can be available as early as initial diagnosis. Palliative care is available to patients with any stage of cancer. It is often provided in combination with treatment.

The palliative care team consists of different healthcare specialists. This may include physicians, nurses, social workers, and nutritionists. The team may have physical, occupational, and speech therapists and pain management specialists. The team may also include spiritual or religious leaders. Working with a team of experts from different specialties is often called “multidisciplinary care”. It is important to work with a “multidisciplinary” care team as each expert brings a specific skillset. This is helpful when making decisions about treatment and side effect management. The palliative care team will work together with you and the person you are caring for. They will also work together with the cancer treatment team. This will help make sure the treatment plan aligns with the patient’s goals and values.

Palliative care addresses physical, social, emotional, and spiritual concerns during treatment. The palliative care team anticipates and helps manage difficult symptoms, pain, and side effects. They also help ensure the patient’s care is coordinated.

This type of care can be offered in a hospital setting, an outpatient clinic, or a skilled facility. It can also be offered in assisted living or even at home. Palliative care is often covered by Medicare, Medicaid, and most insurance plans. Contact your loved one’s healthcare plan to know what exact costs are covered.





WHAT IS HOSPICE CARE?

If at some point ongoing treatment is no longer effective or helpful, the care team may recommend **hospice care**. Hospice care is another type of supportive care. During this type of care, active cancer treatments are stopped. The focus is on your loved one's comfort, pain management, and quality of life.

This form of care also includes a team of multiple experts. The hospice team may include physicians, nurses, and social workers. It may also include home health aides, spiritual or religious leaders, and specialty trained volunteers. Each team member works together to support the person diagnosed, their caregivers, and loved ones. They provide medical assistance to support the patient as they cope with any remaining symptoms. They also offer social, emotional, spiritual, and grief support.

Hospice care can be provided at facilities like a nursing home, hospital, or designated hospice center. It is also offered in a home setting. During this time, the hospice care team will provide regular check-ins and visits. A team member is typically available by phone 24 hours a day, seven days a week to provide support. Most insurance plans will cover the cost of hospice care. Talk with your loved one's healthcare plan to know what exact costs are covered.

At any time, you and the person you are caring for can request information about hospice care. Choosing to enroll does not have to be a permanent decision. If your loved one decides that they would like to begin treatment again, that is OK. They can talk with their doctor about returning to hospice care at any point.

DID YOU KNOW?

Some healthcare organizations and home care agencies offer both palliative and hospice care. Talk with them about what services they provide. Ask them to describe the differences between each option. Always advocate for you and your loved one. Get all the information you need to make an informed decision.

SHARED DECISION-MAKING AS A CAREGIVER

At times, you may need to support your loved one when making treatment decisions. Being an active member in the decision-making process is key. This ensures any questions or concerns you may have as the caregiver get addressed.

Talking with your loved one about supportive care options may be difficult. Still, this is an important step early on. Ask the healthcare team about these services. This way you will understand how these options can help. You can also bring up any treatment or personal goals you both have. By knowing what is available early on, you both can take full advantage of these services if the time comes.

If you need support advocating for yourself and your loved one, know that there are professionals that can help. Talk with a social worker, nurse navigator, or patient navigator. Their role is to help you both through this process. They can get you connected to the right care at the right time.

Open to Options®

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with the care team. **Call 888-793-9355** to schedule an appointment or to find a Cancer Support Community or Gilda's Club location near you.

NAVIGATING THE COSTS OF CARE

Even with a healthcare plan, cancer care can be expensive. Keeping up with these costs can also be overwhelming. Still, there are many resources that can help:

Talk with the healthcare team about the costs related to your loved one's care. Ask if there are any resources available to help with your loved one's treatment costs.

Ask for a referral to an oncology social worker or financial counselor. These experts can help you manage financial concerns. They can also connect you to local or national nonprofit organizations for financial support.

Ask about what resources may be available through your loved one's healthcare plan.

If the care center is far away, ask if there are financial resources that can help cover travel costs.

The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of care, visit:
www.CancerSupportCommunity.org/Help-Managing-Cancer-Costs



PLANNING AHEAD

Learning that a person close to you has cancer can change the way you think about things. You both may begin to make different choices than you did before. It is also common to have thoughts or concerns about the end of life. This may become a source of worry and sadness.

Planning ahead can help you feel more in control during this time. This includes making sure any legal documents are in order. **Advance care planning** is the ongoing process of making decisions about what a person wants their care to look like. These decisions are usually communicated through these documents:



Will – a document that plans for how a person's money or property will be handled. It identifies any legal guardians for children under the age of 18. It also includes details and plans for any pets.



Living will or advanced directive – a document that details the patient's wishes about medical treatment if a time should come when they can no longer express their wishes and/or choices.



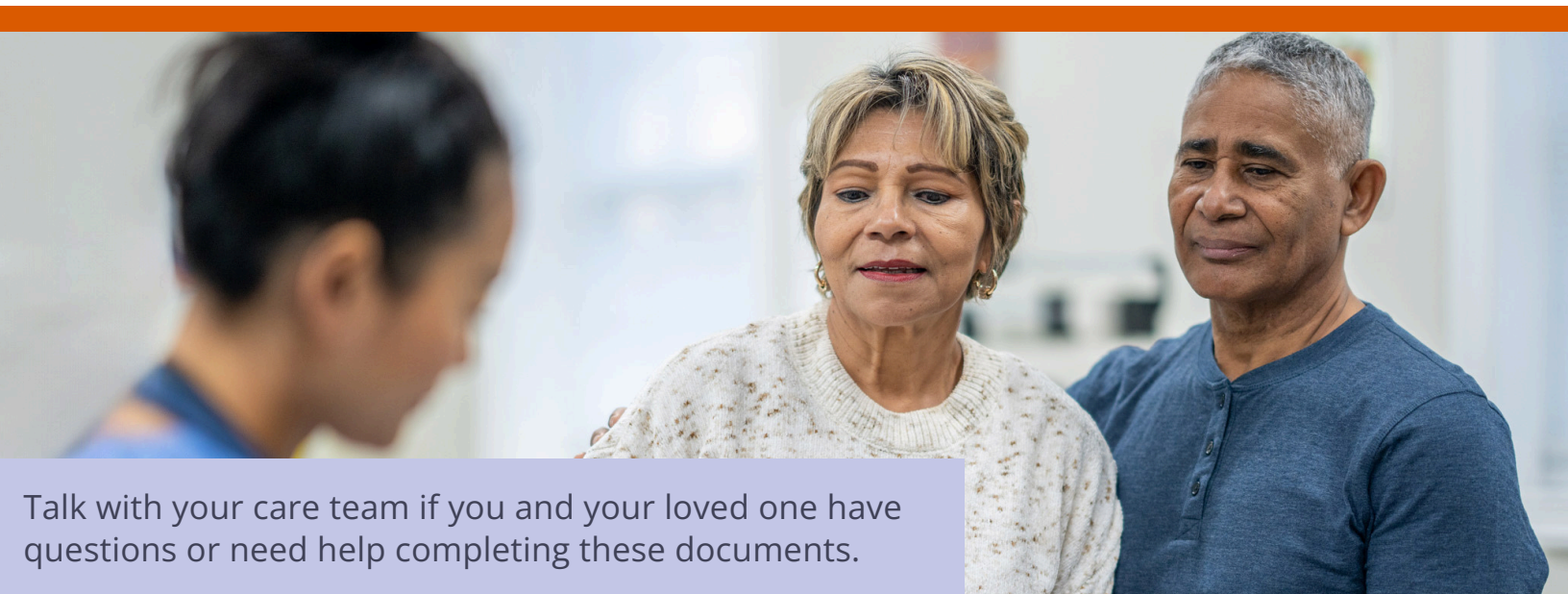
Health care proxy or medical power of attorney – a document that allows the patient to name a trusted person to make decisions about their medical care if they can no longer do so.



Financial power of attorney – a document that names a trusted person who is able to make financial decisions and payments for the patient's health care needs if they are unable to do so themselves.



Do Not Resuscitate (DNR) – an order the doctor writes on the patient's chart if they do not want any action taken in the event of a cardiac or respiratory arrest. This is used if a person stops breathing or their heart stops working. The order says that the patient does not want to be put on machines that will keep their body alive.



Talk with your care team if you and your loved one have questions or need help completing these documents.

COPING WITH STRESS & THE EMOTIONAL IMPACT OF CANCER

The cancer experience can bring up a lot of stress and emotions. You may feel like you have too much going on between caregiving and other roles. It may also be difficult to learn that the person you are caring for may want or need to consider hospice. This may bring about feelings of grief, sadness, or even anger.

You are not alone in feeling the emotional effects of this role. It is important to take care of yourself during this time. This includes both your physical and mental health.

As a caregiver, take time to reflect on how you are feeling and coping as things change. Think about how you manage when things become challenging or stressful. Then consider ways you may want to develop more healthy coping skills.

Some ways to cope and maintain your mental health as a caregiver, may include:

- 1** Identifying your support network—keep in mind friends and loved ones you can reach out to and talk with
- 2** Asking the cancer care team if there are resources or support groups available for caregivers
- 3** Connecting with a therapist, social worker, psychologist, and/or community or spiritual leader to talk with about your experiences
- 4** Seeking out services, like respite care, if you need a short break from your caregiving tasks
- 5** Connecting with a local CSC or Gilda's Club location for support
- 6** Connecting with other caregivers to exchange ideas and coping strategies on CSC's Caregiver Support discussion forum through **MyLifeLine.org**

It is important to recognize your feelings, like sadness or anxiety. You may also experience other challenging and unexpected emotions. These may include anger, resentment, or guilt. While these feelings are common, some may last for a long time. Be mindful if they begin to impact daily life. If so, seek support from a mental health specialist or social worker. Ignoring these feelings may lead to isolation and other issues. Speaking with a specialist early on is important. They can give you the tools to problem-solve, prevent symptoms from worsening, and get to a better place.

To learn more about Coping with Mental Health Concerns, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

Making decisions around supportive care options can be complicated and emotional. Yet, having these services available can bring some relief during a difficult time. With both palliative and hospice care, everyone involved and impacted by cancer has the chance to receive support. These forms of care ensure that any concerns you all have are heard and correctly addressed. The resources at the end of this piece can help you and your loved one navigate these important decisions.



CAREGIVING RESOURCES

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Caregivers

National Alliance for Caregiving

202-918-1013 | www.Caregiving.org

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

MENTAL HEALTH RESOURCES

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

Cancer Support Community

888-793-9355 | www.CancerSupportCommunity.org/Coping-Grief-Loss

National Alliance for Caregiving

202-918-1013 | www.Caregiving.org

National Alliance on Mental Illness

1-800-950-NAMI (6264) | www.NAMI.org

American Cancer Society

800-227-2345 | www.Cancer.org

MentalHealth.gov

www.MentalHealth.gov

National Cancer Institute

www.Cancer.gov/About-Cancer/Coping/Feelings

National Suicide Prevention Hotline (U.S.)

800-273-8255 or 988

Substance Abuse and Mental Health Services Administration

1-800-662-HELP (4357) | www.SAMHSA.gov

CANADIAN MENTAL HEALTH RESOURCES

Suicide Prevention Service - Canada

833-456-4566 or text 45645

Hope for Wellness Helpline - Canada

1-855-242-3310 | www.HopeForWellness.ca

Wellness Together - Canada

text WELLNESS to 741741 for immediate crisis support

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.

Services at Local CSCs and Gilda's Clubs — With the help of nearly 200 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:

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 secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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.

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

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