National Comprehensive Cancer Network®

2026

NCCN Guidelines for Patients®

Cancer care recommendations from leading experts at the National Comprehensive Cancer Network® (NCCN®)

Caregiving for People With Cancer



Made possible by National Comprehensive Cancer Network® Foundation

Available online at NCCN.org/patientguidelines



NCCN Guidelines for Patients®

The essential guide for people facing cancer.

Based on care recommendations from leading cancer experts.

Explains high-quality cancer care provided at state-of-the-art cancer centers.

Reviewed and revised every year.

Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).

Because cancer care is always evolving, NCCN develops and frequently updates evidence-based cancer care recommendations used by health care providers worldwide. These recommendations are known as the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines for Patients plainly explain expert recommendations, so you can talk with your care team about the best care for you.

This patient guide was developed and reviewed by experts from NCCN Guidelines® panelists and collaborators.

View the NCCN Guidelines for Patients free online: NCCN.org/patientguidelines

Find an NCCN Cancer Center near you: NCCN.org/cancercenters

Learn how the NCCN Guidelines for Patients are developed: NCCN.org/patient-guidelines-process

Connect with us



@NCCNorg @NCCNVideo NCCN @NCCNorg

Supporters

National Comprehensive Cancer Network® Foundation

We translate complex cancer care into trusted guidance and fund the next generation of researchers shaping tomorrow's care.

NCCN Foundation gratefully acknowledges the following corporate supporters for helping to make available these NCCN Guidelines for Patients: Alexion, AstraZeneca Rare Disease; AVEO Pharmaceuticals, Inc.; Corcept Therapeutics; Janssen Biotech, Inc.; Kite, a Gilead Company; Merck & Co., Inc.; Novartis Pharmaceuticals Corporation; and Sobi.

NCCN independently adapts, updates, and hosts the NCCN Guidelines for Patients. Our corporate supporters do not participate in the development of the NCCN Guidelines for Patients and are not responsible for the content and recommendations contained therein.



The way forward starts here.

National Comprehensive Cancer Network® Foundation

Give Now

Contents

4 Chapter 1
About caregiving

10 Chapter 2
Learn the basics of cancer

21 Chapter 3
How to make a caregiving plan

30 Chapter 4
How to be part of the cancer care team

38 Chapter 5
Providing patient care and support

49 Chapter 6
Take care of yourself, too

57 Chapter 7
Other resources

61 Words to know

62 NCCN Contributors

63 NCCN Cancer Centers

64 Index

NCCN Guidelines for Patients and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. No one, including doctors or patients, may use the NCCN Guidelines for Patients for any commercial purpose and may not claim, represent, or imply that the NCCN Guidelines for Patients that have been modified in any manner are derived from, based on, related to, or arise out of the NCCN Guidelines for Patients. The NCCN Guidelines are a work in progress that may be redefined as often as new significant data become available. NCCN makes no warranties of any kind whatsoever regarding its content, use, or application and disclaims any responsibility for its application or use in any way.

NCCN Foundation seeks to support the millions of patients and their families affected by a cancer diagnosis by funding and distributing NCCN Guidelines for Patients. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of innovation in cancer research. For more details and the full library of patient and caregiver resources, visit NCCN.org/patients.

National Comprehensive Cancer Network (NCCN) and NCCN Foundation
3025 Chemical Road, Suite 100, Plymouth Meeting, PA 19462 USA

PLEASE NOTE that by downloading/using this NCCN Content, you agree to the terms of the NCCN End-User License Agreement (https://www.nccn.org/end-user-license-agreement) and you MAY NOT distribute this Content or use it with any artificial intelligence system, machine learning model, or large language model or other artificial intelligence tool.

Copyright © 2026 National Comprehensive Cancer Network, Inc. All Rights Reserved.

1
About caregiving

5 What is a caregiver?

6 What does a caregiver do?

9 What can you expect as a caregiver?

9 How can you get help?

Caregivers are an essential part of the cancer care team. However, there's more to being a caregiver than most people realize. One big part of being a caregiver is speaking up for your loved one.

What is a caregiver?

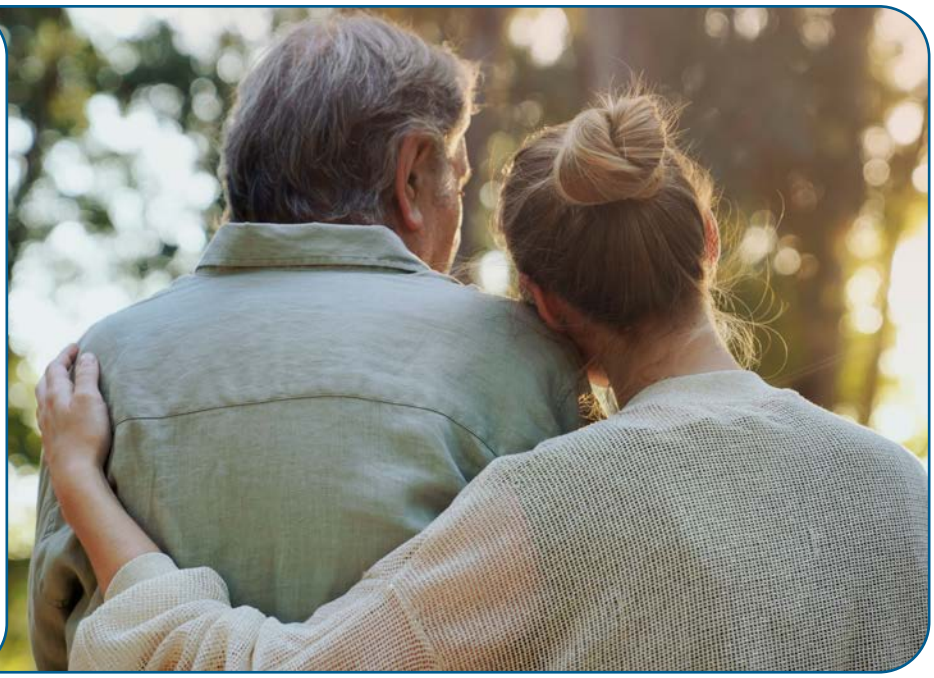
If you spend some or all of your time helping someone else get through cancer, then you're a caregiver.

This guide uses the term **caregiver** to refer to a person who provides regular care or help to a loved one with cancer. Some people use the terms carer or care partner.

Caregivers provide care in different ways, including physical, personal, and hands-on care. A caregiver is also a partner, an advocate, a companion, and a source of emotional support for their loved one.

In this guide, a **loved one** describes the person being cared for. A loved one may be a spouse, partner, parent, child, grandparent, sibling, other relative, close friend, or another person you choose to care for.

Caregivers are committed to helping their loved ones. Your responsibilities as a caregiver may change over time. Many caregivers report that they wish they had been more prepared. Knowing what to expect can be helpful as you navigate new challenges and the emotional impact of being a caregiver.



What does a caregiver do?

While the loved one is the primary decision-maker, the caregiver is an essential partner in their care.

Some caregivers manage all or almost all of their loved one's care at home. Other caregivers help their loved one with just a few responsibilities.

Some caregivers live with their loved one and provide care around the clock. Other caregivers live far from their loved one and provide help remotely or occasionally in person.

Caregiving responsibilities usually change over time, depending on the loved one's treatment, health, and personal circumstances. Responsibilities can increase, decrease, or evolve into different responsibilities.

Some caregivers start by providing just a little help, and don't see themselves as caregivers until they consider all the help they've been providing. See **Guide 1**.

Unlike other members of the cancer care team, caregivers don't have a roadmap or formal training for their role. There are no certifications for being a caregiver.

Most caregivers are given little or no guidance on how to take care of a loved one. They learn "on the job." Few individuals receive specialized education to help their loved one with daily activities, emotional support, or medical care—not to mention how to take care of their own health and well-being.

Caregiving by the numbers

Nearly **1 in 4 American adults** is currently a **caregiver**

Caregivers of adult loved ones provide care for an average of **5.5 years**

40% of caregivers **live in the same home** as their loved one

About **1 in 4** caregivers take care of **2 or more** loved ones

About **3 in 5** caregivers help with **medical/nursing** tasks

2 in 3 caregivers communicate with their loved one's **health care professionals**

70% of caregivers are also employed while being a caregiver

Source: Caregiving in the US 2025

Guide 1
Self-assessment: Are you a caregiver?

☐		Schedule medical appointments
☐		Drive your loved one to medical appointments and treatments
☐		Take notes during medical appointments
☐		Provide emotional support
☐		Give medicines or injections
☐		Communicate with members of the care team
☐		Share information with family members and friends
☐		Shop for groceries
☐		Prepare meals
☐		Help with changing clothes
☐		Help with using the bathroom
☐		Clean and do other housework
☐		Wash the laundry
☐		Manage health insurance and finances

Here are some examples of the roles and responsibilities of a caregiver. This list doesn't include all the duties caregivers perform. And not all of these responsibilities apply to every caregiver.

- **Driver/courier** – Drive a loved one to and from appointments. Pick up medications. Go shopping for groceries.
- **Medical teammate** – Schedule and attend medical appointments. Maintain copies of important medical documents. Help a loved one understand their diagnosis, prognosis, or treatment options. Advocate for the loved one with the cancer care team. Assist the loved one with treatment decisions.
- **Point of contact** – Keep family and friends updated on the loved one's condition (to give the loved one a break from constant communications).
- **Emotional supporter** – Provide companionship. Listen to the loved one's thoughts and feelings. Offer encouragement. Suggest or manage positive social engagements or outings.
- **Housekeeper** – Clean and keep up a loved one's home. Cook meals for the loved one and/or loved one's family. Assist with childcare. Provide pet care.
- **Personal helper** – Assist with activities of daily living, such as getting dressed, bathing, using the bathroom, and transferring safely in or out of a chair or bed.
- **Health care assistant** – Organize and give medicines. Monitor temperature and other symptoms. Administer medications or change dressings. Ensure adequate nutrition and physical activity. Arrange nursing visits or other support.
- **Financial associate** – Keep track of medical bills. Navigate health insurance difficulties. Manage or assist with household finances and paying bills.
- **Legal assistant** – Supervise your loved one's legal concerns, such as an advance directive, power of attorney, and will.

Because you'll wear so many hats—and change them quite often—you'll become an expert at being flexible and adapting to new circumstances and challenges.

> **"Caregivers are the unsung heroes of a patient's cancer journey. They are underrecognized yet play such a critical role."**

What can you expect as a caregiver?

Caregiving can be rewarding. It can fill you with personal pride, the satisfaction of helping others, a greater sense of purpose, and a deeper connection with a loved one.

But caregiving can also be stressful and, at times, overwhelming. You may feel anxiety, worry, helplessness, exhaustion, grief, and even anger.

You may have good and bad feelings at the same time—even in the same moment. That's okay. It's normal for caregivers to feel bad sometimes and to feel good sometimes.

How can you get help?

Most caregivers need help at one point or another.

Some caregivers suddenly find themselves taking on many responsibilities at once, due to a loved one's abrupt change in health. Other caregivers may help a loved one with a single, simple task but then gradually take on more and more responsibilities.

That's where this guide comes in. There's **a lot** to learn about caregiving and cancer. This guide offers practical information and encouragement to enhance your journey as a caregiver for a person with cancer.

If you're new to caregiving, this guide will help you make a good start. If you've been caregiving for a while but still don't have all the answers, this guide will direct you further along the way.

This guide won't provide every answer, of course. But it will help you learn how, when, and where to get more help or information for your loved one's health and your own.

You'll feel more comfortable asking questions, more confident that you're providing good care and assistance, and more connected to your loved one, the cancer care team, and maybe even other caregivers.

2
Learn the basics of cancer

11 What is cancer?

13 What causes cancer?

14 How is cancer diagnosed?

15 How is cancer treated?

17 Side effects of cancer treatments

18 If cancer goes away

19 If cancer comes back

19 Survivorship

19 End-of-life care

20 Key points

20 Questions to ask the care team

If you want to know more about cancer, this is the place to start.

What is cancer?

Cancer is a disease in which certain cells in the body grow out of control.

The human body has trillions and trillions of cells. Cells that are normal follow the body's rules. Normal cells increase in number only when they're needed. They die when they're old or damaged.

Cancer cells don't follow the rules. They can multiply quickly and avoid dying. They can crowd out normal cells and take their place. When many cancer cells collect together, they can form a tumor.

As cancer grows and spreads, it can overwhelm normal cells. This overload of cancer cells can eventually damage the body and cause symptoms. See **Guide 2**.

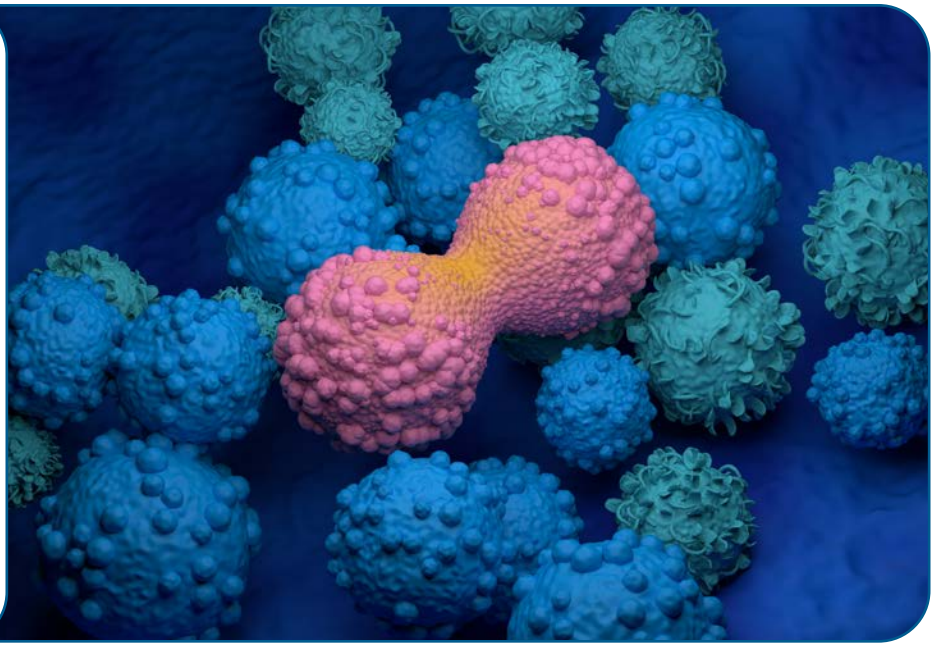
Although all cancers share a similar pattern of growth, cancer isn't a single disease. There are more than 200 distinct types of cancer, each with different characteristics. What's more, each person's diagnosis is unique.

Cancer symptoms

Each type of cancer has symptoms that can be very different from other cancers. Even cancers of the same type can have different symptoms. However, not everyone with cancer develops symptoms.

Further, other conditions and diseases often have the same symptoms that cancer has. So having symptoms doesn't automatically mean it's cancer. This is why testing is so important—doctors and the care team need to find the correct diagnosis for the condition.

Cancer cells typically look different from normal cells under the microscope. Cancer cells can multiply quickly by dividing themselves over and over.



Guide 2
Some common symptoms of cancer

Each type of cancer has symptoms that can be very different from other cancers. Even cancers of the same type can have different symptoms. There are more symptoms of cancer than those listed here, but these are some of the most common.

Fatigue or extreme tiredness that doesn't get better with rest	**Weight loss** for no known reason
Nausea and vomiting	**Mouth or tongue sores**
Loss of appetite	**Trouble swallowing**
Pain anywhere in the body that doesn't go away or gets worse, especially if it's new or occurs for no known reason	**Swelling or lumps** that can be felt under the skin (especially in the breast, neck, stomach, groin, or underarm)
Skin changes, such as yellowing, darkening, or redness of the skin; sores that don't heal; or a new mole or change in a mole	**Change in bowel habits**, such as constipation or diarrhea that doesn't go away, blood in your poop, or a change in how your poop looks
Cough or hoarseness that doesn't go away	**Excessive bleeding or bruising** for no known reason
Heartburn or indigestion after eating that keeps occurring	**Bladder changes**, such as pain when urinating, blood in the urine, or needing to urinate more or less often
Fever or night sweats that keep occurring	**Abnormal vaginal bleeding**
Headaches or seizures	**Vision or hearing problems**

What is early, advanced, and metastatic cancer?

Some cancers are diagnosed when the cancer is small or growing slowly. This is often called **early cancer**.

Other cancers are diagnosed when the cancer has advanced. **Advanced cancer** has grown larger or progressed further in the body than early cancer and usually needs stronger treatment.

Cancer that starts in one part of the body and spreads to another part is called **metastatic cancer.** Metastatic cancer may be very serious.

What causes cancer?

Doctors and researchers are learning more and more about cancer all the time. One thing they know is that cancer usually starts with a change or abnormality in certain cells. This change is frequently called a mutation.

A mutation can occur all by itself (a somatic mutation). Or it can be passed down in families (a hereditary mutation).

Either type of mutation can bring about a change in the body's cells, causing the cells to become abnormal. As these abnormal cells grow and spread, they become cancer.

Cancer is unpredictable—it doesn't follow a straight course. As a result, caregiving is unpredictable, too.

Two basic kinds of cancer

Cancer can be classified into 2 basic categories: solid cancer tumors and blood cancers.



A solid cancer tumor is an accumulated lump of cancer cells. The tumor is typically named for the area of the body where it formed, such as the lung, breast, or prostate.



A blood cancer doesn't develop as a physical lump in a specific organ. Rather, blood cancer cells circulate throughout the body. Leukemia and lymphoma are common blood cancers.

How is cancer diagnosed?

A diagnosis means identifying an illness by using tests. These tests measure how much and how quickly the cancer is growing.

Individuals being evaluated for cancer typically have many tests. Tests are used to plan treatment, to find out how well treatment is working, and to check if the cancer has come back after treatment.

Sometimes an individual has the same tests over and over again throughout their cancer experience.

Common tests for cancer include blood tests and imaging scans. A biopsy, in which a sample of tissue is removed from the body and tested, is still the main method of diagnosing cancer. In recent years, genetic tests and biomarker tests have also become common. See **Guide 3**.

Guide 3
Tests for diagnosing cancer and planning treatment

These are the most common types of tests and procedures for diagnosing cancer and planning treatment. Not everyone will receive all these tests.

 **Blood tests**	If a blood test shows an unusual result with your blood cell count or blood chemistry, it's a sign that something could be wrong.
 **Medical and family history**	Your health and that of your blood relatives might suggest a family history of cancer.
 **Imaging scans**	Imaging scans, like x-rays, CT, MRI, and PET, take pictures of the inside of the body to find cancer.
 **Biopsy**	A biopsy is a surgical procedure that removes a small tissue sample that is tested for evidence of cancer.
 **Biomarker test**	Biomarker tests analyze samples of blood, tissue, or urine to look for molecular or genetic markers linked to cancer.

How is cancer treated?

No single cancer treatment is best for everyone. Different types of cancer often require specific types of treatment.

Treatment is based on certain features of the cancer, as well as the individual's overall health and personal preferences.

The best treatment option often includes more than 1 type of therapy.

Some cancers can be cured. But even if they can't, most cancers can be treated to prevent or lessen symptoms and often prolong life.

Common treatments for cancer include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, clinical trials, and other therapies.

Types of cancer treatments

Although many people with cancer receive more than 1 type of therapy, very few receive all these therapies.



Surgery aims to remove as much cancer as possible by carefully cutting it out of the body.

Chemotherapy is a drug treatment that destroys cancer cells as well as some other cells throughout the body.

Radiation therapy uses high-energy x-rays or other types of radiation to kill cancer cells.

Immunotherapy is treatment that helps the body's immune system find and destroy cancer cells.

Targeted therapy is a drug treatment that targets specific mutations, proteins, or other features of certain cancer cells.

Clinical trials are another way some patients can get treatment. They're medical studies that test new ways to fight cancer.

Other therapies are given mainly for very specific cancers. These treatments include hormone therapy, stem cell transplant (also called bone marrow transplant), CAR-T cell therapy, thermal therapy, and more.

Supportive care is for relieving cancer symptoms and the side effects of cancer treatment. Sometimes called palliative care, supportive care also provides a range of other services. Supportive care is for everyone with cancer, not just for those at the end of life. Starting supportive care early, soon after diagnosis, may be best.

More information on supportive care can be found in *NCCN Guidelines for Patients: Palliative Care,* available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Tips to get ready for your loved one's appointments

- Help your loved one prepare questions before going to the visit.
- Write down or print out a list of current medications. Make copies so you can hand them out as needed.
- Bring a notepad and pen to take notes during the appointment.
- Be ready to ask questions if something is confusing or unclear. Don't simply nod your head or pretend to understand.
- At the visit, introduce yourself as the caregiver. Don't feel intimidated by doctors and staff.
- If you forget to ask a question during a visit, write it down so you can ask it later.

Treatment for cancer is moving away from one-size-fits-all therapies toward more precise and personalized therapy.

Side effects of cancer treatments

All treatments for cancer can cause side effects.

Some people have many side effects while others have few. Some side effects can be very serious. Others are simply unpleasant.

Most side effects appear soon after treatment starts and go away after treatment ends. Other side effects are long-term or may appear years later.

Side effects depend on many factors, especially the type, length, and dose of treatment. See **Guide 4**.

Guide 4
Common side effects of cancer treatments

	**Surgery**	• Pain • Infection • Blood clots • Bleeding
	**Chemotherapy**	• Fatigue • Hair loss • Low blood cell counts • Nausea and vomiting • Loss of appetite • Constipation and diarrhea • Changes in thinking and memory
	**Radiation therapy**	• Fatigue • Skin redness or irritation • Inflammation
	**Immunotherapy**	• Fatigue • Skin redness or irritation • Flu-like symptoms (fever, chills, aches) • Diarrhea
	**Targeted therapy**	• Fatigue • Skin rash or irritation • Nausea and diarrhea • High blood pressure

Some of the **most common side effects** of cancer treatment include pain, distress, nausea and vomiting, and fatigue. Fatigue isn't just feeling tired. It's an overwhelming exhaustion that doesn't get better with regular rest and sleep.

Other common side effects include weight changes, diarrhea and constipation, hair loss, and changes in blood cell count. Changes in blood cell count can cause problems like tiredness, shortness of breath, and lightheadedness.

Still other side effects are incontinence, sexual difficulties or dysfunction, blood clots, and mouth problems. Mouth problems include dry mouth, infections, sores, tooth decay, and sensitivity to hot and cold food and beverages.

Another common side effect due to treatment is problems with thinking or remembering, often called chemo brain.

More information on distress, fatigue, nausea and vomiting, changes in blood cell count, blood clots, and other side effects can be found in the following patient guidelines, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.

- *NCCN Guidelines for Patients: Distress*
- *NCCN Guidelines for Patients: Fatigue and Cancer*
- *NCCN Guidelines for Patients: Nausea and Vomiting*
- *NCCN Guidelines for Patients: Low Blood Cell Counts*
- *NCCN Guidelines for Patients: Blood Clots*

Treatment for side effects

Many side effects can be managed with supportive care. Some can even be prevented. Ask the cancer care team for a complete list of short- and long-term side effects and how they can be managed.

If cancer goes away

Treatment can make cancer go away for a period of time or perhaps for the rest of a patient's life, depending on the cancer, the treatment, and other factors. This is referred to as remission.

Remission

Remission is when there's no clinical evidence of cancer.

For some people, remission may mean no further cancer in their lifetime. For others, remission may be a short respite.

Monitoring

After treatment, or during remission, your loved one will probably need further testing for any sign that the cancer may come back. This period of regular, ongoing testing is often called **watching and waiting.** It's also called **monitoring or surveillance.**

Because there's no active treatment during this time, some people consider watching and waiting more stressful than treatment itself because they're worrying and wondering about what could happen next.

If cancer comes back

Recurrence/relapse

Cancer can change over time. Sometimes, cancer cells become resistant to treatment or they find ways to avoid it. When this happens, treatment can stop working.

As a result, the cancer can come back, sometimes in a more advanced or aggressive form. When cancer comes back after treatment, it's called **recurrence** or **relapse.**

Progression

Sometimes cancer keeps growing or getting worse even with treatment. This is called **progression.**

If cancer comes back or gets worse, stronger treatment or a combination of treatments is often needed.

Survivorship

Survivorship refers to a new phase of life that begins at diagnosis and continues throughout life.

Survivorship care aims to improve the health, well-being, and quality of life of people living with or cured of cancer. It addresses the lasting impact of cancer and its treatment.

More information on survivorship can be found in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living* and *Survivorship Care for Cancer-Related Late and Long-Term Effects,* available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Caregiver's Corner

Go outside for a walk. Getting out in nature, breathing fresh air, and stretching your muscles is a natural pick-me-up.

If you can't spare the time for a long walk, take a short stroll in the park. If time is really limited, step outside and take a deep breath.

For more self-care tips, see *Chapter 6: Take care of yourself, too.*

End-of-life care

End-of-life care includes medical, psychological, and spiritual support for people who are close to the end of life. Its purpose is comfort, not cure.

End-of-life care gives people the best life possible with the time they have left. The goal is to minimize your loved one's pain and make sure they can leave this world comfortably and with dignity. Care can be provided in the home, hospice facility, or other setting.

Providing support for family members is a key part of end-of-life care. Most programs offer counseling and support groups for caregivers and family members, including support after the patient has died.

Key points

- Cancer is a disease in which certain cells in the body grow out of control.
- Cancer usually starts with a change or abnormality in certain cells. This change is frequently called a mutation.
- Treatment is based on specific features of the cancer, as well as the individual's overall health and personal preferences.
- Common treatments for cancer include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, and sometimes clinical trials.
- Remission is when there's no clinical evidence of cancer.
- Progression means the cancer continues to grow, even with treatment.
- For recurrent, relapsed, and progressive cancer, more intense treatment or several types of treatment may be given.

Questions to ask the care team

- How soon will we know the results of the tests and who will explain them to us?
- What are the treatment options?
- How soon should treatment begin?
- What are the likely side effects of treatment?
- How can we get a second opinion?

What's next?

Now that you have a basic understanding of cancer and its treatments, it's time to consider the unique needs of your loved one dealing with cancer.

Read about managing your loved one's needs in the next chapter.

3

How to make a caregiving plan

22 Identify your loved one's needs

24 Make a caregiving plan

26 Gather a caregiving team

28 Put the plan into action

28 Key points

29 Questions to ask your loved one

The cancer diagnosis came as a shock. Suddenly you're driving your loved one to appointments, taking notes, picking up medicines, and more… You're a caregiver, and you realize there's a lot to be done. It's time to get organized.

If you're a new caregiver, your first priority will be to identify and organize your loved one's needs. This can help reduce stress and increase your confidence as a caregiver. It can also improve communication and safety, along with allowing more quality time with your loved one.

Identify your loved one's needs

Your loved one should be at the center of all decisions about caregiving. So it's important to ask them directly about their care needs, instead of assuming or guessing. This opens up communication between you and your loved one. And it empowers your loved one to be involved in their own care.

Also ask your loved one if there are tasks they'd rather handle on their own.

Talking about care needs can be difficult for you and your loved one. You and your loved one may have different ways of communicating and coping. They may be reluctant to ask for help, or they may feel overwhelmed by the changes they're going through.

In addition, a cancer diagnosis can make a person feel like things are out of their control. Reassure your loved one that they'll make the decisions and that you'll work together to meet their needs.

All caregiving ideas should be focused on, discussed with, and approved by your loved one. Ask your loved one what's important to them.



You may find that your loved one has been holding onto these thoughts but hasn't wanted to voice them. Once you ask about their care, they may be relieved that they "have permission" to share all the thoughts and feelings they've been holding onto.

On the other hand, if your invitation to discuss caregiving results in a flat rejection, be patient. They may find it overwhelming to talk about what they want and they may need more time to think about it.

You can revisit the discussion later if your loved one is more open to talking about areas where they need assistance. Consider starting off by offering help with one task at a time. In the meantime, let your loved one know you're there to listen and help.



If you're a caregiver to your spouse or partner

A cancer diagnosis affects both people in a relationship. Be prepared for a number of possible changes.

Roles reverse. If the "decision-maker" in a relationship develops cancer, the other partner may have to step in to make decisions. If the person who manages the finances becomes too fatigued or too sick, their caregiver/partner may need to take over responsibilities like paying the bills, balancing the checkbook, and budgeting household income. If the person who manages the home has cancer, the other partner will need to cook, clean, and organize.

Intimacy changes. Shifting from spouse to caregiver can affect the dynamic of the relationship. Cancer symptoms and the side effects of treatment can also take a toll on physical and emotional intimacy. Pain, fatigue, and stress—to name a few—can dampen desire and romance. Treatment can affect sexual health as well.

Relationships deepen. Cancer is often stressful. Yet there are some couples who find that facing the adversities of cancer brings them closer together and deepens their relationship. Even if physical intimacy changes, emotional intimacy can continue to grow.

The key to surviving these ups and downs is open and honest communication plus patience. Talk with your partner if you feel them growing distant. Or reach out to a counselor or therapist for help.

It's important to know that needs change over time, from diagnosis to treatment, from recovery to recurrence, and beyond. Check in with your loved one throughout their cancer journey to make sure their needs continue to be met.

Once you've received the go-ahead from your loved one about their care needs, the next step is to think about or draw up a list of these responsibilities for the overall care plan.

Cancer caregivers are often surprised by how much hands-on care they need to provide—and how little training they get for it.

Make a caregiving plan

Making a care list

Making a list can help you identify all the tasks that need to be provided.

It can also help you stay organized and on top of things. The cancer experience can sometimes be a rollercoaster ride—it may help to anticipate changes and plan ahead so you don't suddenly have too much to do during the ups and downs.

You can use **Guide 1** on page 7 as a starting point for making a checklist or inventory of your loved one's needs. You don't have to pin down every task your loved one needs—a basic working list is enough to get started.

Making a plan

Once you have your list of responsibilities, it's time to organize them into a plan. A caregiving plan is a list of your loved one's needs, organized by details such as time, frequency, availability of the person who has

When talking about a caregiving plan for the first time, make sure your loved one knows you're not trying to take away their independence—you only want to make sure their needs are met.



the responsibility for providing that care, and other factors.

Keep in mind that there's no "correct" way to be a caregiver or to provide care. Give yourself grace—you're doing your best during a really difficult time. Know that the caregiving plan will change as time goes on. Stay flexible as needs shift or new needs arise.

An essential part of developing a caregiving plan is to include others who can help handle some of the responsibilities. No one person can do it all. Recruit family, friends, and neighbors that you trust and are dependable. (More on this in the next section, "Gather a caregiving team.")

Keep in mind that others may not know where to jump in, so it's important to communicate what type of support is needed.



If you're a caregiver to a parent or grandparent

When a parent or a grandparent develops cancer, you may suddenly find you've become the caregiver—instead of them caring for you.

Roles reverse. Getting used to the change in roles can be difficult for both of you. After all, you've been the care recipient since you were born and they've been the caregiver. They may reject your help because they don't want to burden you. And they may not let go of the caregiver role easily.

Plus, losing independence because of aging and illness is tough for any older adult. They'll likely struggle with this change as much as you do.

Balancing caregiving and family. While caring for your parent or grandparent, it's important for you to continue spending time with your family and friends. This can help you feel connected to others with less burnout due to shifting responsibilities.

If you're a parent, it may be helpful to ask other family and friends to babysit or take your child to activities while you're caregiving for your parent or grandparent.

Growing closer. On the upside, caring for your parent or grandparent may bring you closer together in a new and more meaningful way.

When people offer to help, take them up on it!

Here's a basic, step-by-step approach to developing a caregiving plan. Your approach may look different.

- Agree to delegate and share responsibilities (be clear on who does what).
- Assign roles and responsibilities using your list of identified needs and your loved one's priorities. Think about which helpers are best suited to different tasks.
- Plan what to do in an emergency and how to prevent one:
  - Know when to call for emergency help.
  - Know which symptoms mean you should call the care team.
  - Learn how to handle medications safely.
  - Make your home safe, especially to prevent falls.
  - Follow infection precautions when needed.
- Add a list of doctors, specialists, and other care providers (including their phone numbers) to the plan. Also include a list of instructions and medications (including the prescriber).
- Distribute the plan to every team member. Keep everyone in the loop.
- Revisit the plan with the loved one early and on a regular basis.

Gather a caregiving team

When someone is diagnosed with cancer, many friends and family members will ask sincerely if they can do anything to help. When people ask, don't be afraid to answer yes. (See "Practical tips for getting help" on page 27.)

If you're not sure yet what you need help with, ask the person to check back with you in a week, when you've had time to think it over.

How to ask for help

It can be hard for anyone to ask for or to accept help. You may hesitate to ask family members, friends, neighbors, or community organizations for help because you worry you're asking too much or believe you're able to handle things on your own. It can feel easier in the moment to do a caregiving task yourself instead of coordinating help with someone else.

We all need help in our lives at some point. Asking for or accepting help isn't a sign of weakness or that you're giving up. Getting help can make things run more smoothly and allow others a chance to be present for their friend or family member.

Consider accepting help with meals, transportation, childcare, household chores, and respite care. This saves your energy for the things only you can do.

Similar to how you might feel at times, friends and family members may not know what to offer or what's needed from them. Sometimes people have good intentions, but what they offer isn't really what's needed. Try communicating specific tasks, such as dropping off a meal on a certain night or taking the kids to practice.

Keep in mind that it can also be overwhelming to coordinate help from others—you might consider asking someone to be the "point person" to share updates, organize meal trains, or delegate other tasks.

It's also important to identify what you don't want to do or can't do for your loved one. Some caregivers are uncomfortable giving certain medications or caring for surgery wounds. Others aren't physically able to help transfer a loved one from a wheelchair to a bed.

Consider talking with the cancer care team about exploring outside support to help with daily activities or certain tasks. For more on hiring an outside caregiver, see *Chapter 5: Providing patient care and support*.



Practical tips for getting help

- Make a list of tasks that need to be done. Keep the list handy. When someone asks, "What can I do to help?" you'll be ready with a number of necessary tasks to offer them.
- Offer specific tasks. It's good to be flexible but avoid being vague or noncommittal. Helpers will more easily agree to take on a responsibility that involves a specific task to be done at a particular time.
- Take advantage of websites that match helpers with tasks. Create and coordinate a caregiving schedule and a method of communication through Lotsa Helping Hands (lotsahelpinghands.com), SignUpReady (signupready.com), or the Helping Calendar on MyLifeLine (mylifeline.org).
- Cut down on the casseroles by using sites like Meal Train (mealtrain.com) or Take Them A Meal (takethemameal.com), which let helpers schedule a time to bring meals. Or ask for gift cards for food delivery services like Doordash or GrubHub.

Put the plan into action

Once you've identified your loved one's needs and assigned tasks to yourself and others, your plan is ready to be put into action.

Remember, you don't need to have every last task assigned or every detail perfectly ironed out before you put your plan into play. Know that the plan will likely change as time goes on. Stay flexible and be ready to adapt and improvise.

Key points

- Your first priority as a new caregiver is to identify your loved one's needs.
- While you try to meet their needs, also make sure your loved one knows the goal is to help them maintain their independence.
- A caregiving plan is a list of your loved one's needs, organized by details such as time, frequency, availability of the person who has the responsibility for providing that care, and other factors.
- Your loved one's needs will change over time. So be flexible and anticipate that the caregiving plan will change, too.
- An essential part of developing a caregiving plan is to include others who can help handle some of the responsibilities.
- When people ask if they can help, don't be afraid to answer yes.
- Asking for help isn't a sign of weakness or that you're giving up.



Caregiver's Corner

If you're balancing work and caregiving (which most caregivers do), contact your human resources department for support. You may have options.

For more self-care tips, see *Chapter 6: Take care of yourself, too.*

"As a caregiver, remember to say yes and provide a specific 'ask' when others reach out and ask if you need anything."

Questions to ask your loved one

- Which tasks do you want or need help with?
- Are there tasks or responsibilities you would rather do on your own or get outside help with?
- Is there anyone you want me to ask to help?
- Would you consider hiring help for certain tasks?

“Caregiving can slowly become your whole world. Accepting help isn’t stepping away from the person you love. It can give you the space to be their spouse, partner, daughter, son, or friend again, instead of only being their caregiver.”

4

How to be part of the cancer care team

32 You, the advocate

34 The cancer care team

34 How to work with the cancer care team

36 Share observations

37 Key points

37 Questions to ask your loved one

One of your loved one's key needs may be having someone speak on their behalf to the cancer care team. But trying to work with the cancer care team can be intimidating. Here's a stress-free way to get on board.

A cancer care team is a group of doctors, nurses, specialists, and other professionals who work together to treat a person's cancer.

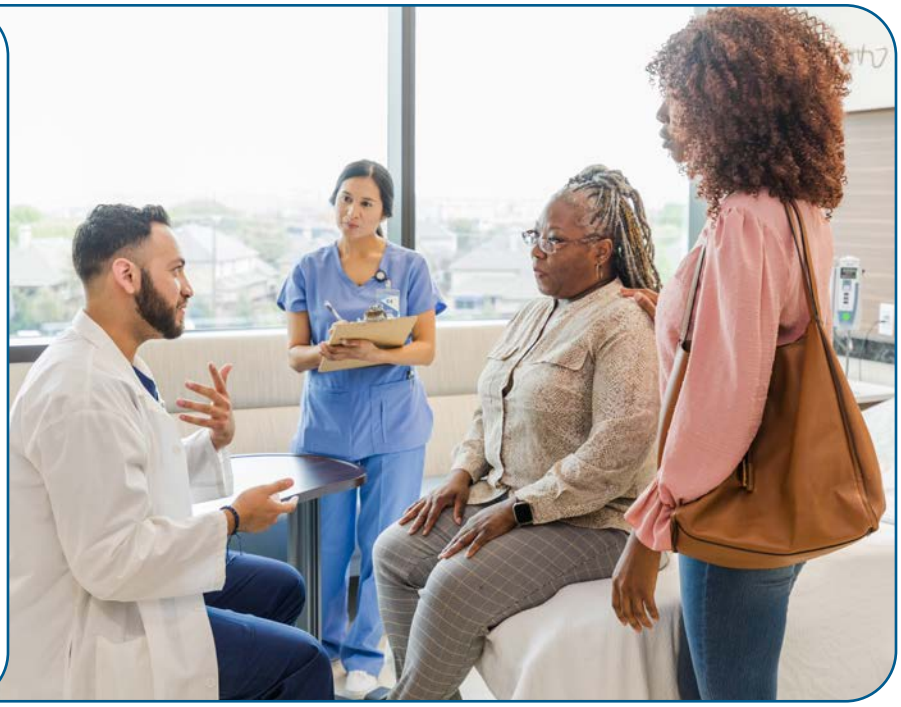
But the central member of the cancer care team is the patient. All decisions made by the team should keep the patient at the center of care.

Why? Because most people want to be involved in decisions about their own health care. When patients are involved in decisions about their care, most experience a greater sense of control, higher satisfaction, and improved quality of life.

Because the patient is such an important member of the cancer care team, they should have an equal voice in making treatment decisions. This is called shared decision-making.

Shared decision-making means working with the cancer care team to create a treatment plan that fits both your loved one's medical needs and their personal goals.

As a caregiver, you can help communicate your loved one's preferences to the cancer care team and explain the team's reasonings to your loved one.



Shared decision-making involves 4 key tasks. Together, your loved one, you, and the cancer care team will:

1. Share information with each other.
2. Each have a say in the decision-making process.
3. Consider both the medical concerns and your loved one's personal values and goals.
4. Make a joint decision on what to do.

"Caregivers are part of the care team. Your observations, questions, concerns, and instincts matter. Write things down, ask the questions—even the ones that feel small—and don't be afraid to use your voice."

You, the advocate

Your loved one may not feel comfortable or well enough to fully participate in shared decision-making and being the center of the cancer care team.

In such cases, the caregiver often steps in as the loved one's advocate. An advocate is simply someone who supports or acts on behalf of another.

Your loved one is important to you, and you want the best possible care for them. As an advocate—also referred to as a care partner—you can help communicate your loved one's preferences to the cancer care team and explain the team's reasonings to your loved one.

Caregivers also help by finding information, talking through options, giving emotional support, and asking questions. It's important to have regular talks with the care team about goals for your loved one's treatment and their treatment plan.

When the entire care team communicates and works together, it benefits your loved one. But feeling tired, stressed, or worried can make emotions harder to control. You'll get more accomplished if you're collaborative, not confrontational, with the care team. It's okay if you need to step away from a difficult conversation.

If you feel like your loved one's needs aren't being met by the cancer care team, ask if there's a clinic or hospital advocate who can help support you.

But before discussing goals and treatment any further, let's first clarify what a **cancer care team** is.

Who's on the cancer care team?



Medical oncologists treat cancer using drug therapy, such as chemotherapy or targeted therapy.



Radiologists interpret the results of x-rays and other imaging tests. An interventional radiologist performs needle biopsies and places ports for treatment.



Surgeons treat cancer by repairing or removing a part of the body, such as a tumor.



Radiation oncologists prescribe and plan radiation therapy to treat cancer.



Hematologists diagnose and treat blood diseases and blood cancers.



Pathologists analyze the cells and tissues removed during a biopsy to provide a cancer diagnosis.



Primary care physicians treat cancer complications, evaluate depression, provide pain care, refer to specialists for other conditions, and more.



Oncology nurses provide hands-on care in the hospital, like giving treatment, managing care, helping with side effects, and answering questions.



Registered dietitians provide guidance on what foods are healthy and suitable for people with cancer.



Palliative care providers include nurses, advanced practice providers, social workers, chaplains, and physicians who specialize in supportive (palliative) care. They provide help for the symptoms of cancer and the side effects of cancer treatment.



Psychologists and psychiatrists help treat and manage issues such as depression, anxiety, or other mental health conditions that can affect how people think, feel, and cope with their diagnosis.



Social workers help people cope with problems in their everyday lives. Oncology social workers specialize in helping people and their families manage practical and emotional concerns of cancer and its treatment.

The cancer care team

Treating cancer requires a team approach. Treatment decisions involve an entire team of cancer professionals—doctors, nurses, specialists, social workers, and other providers—who have knowledge and experience in your loved one's type of cancer and its complications.

This team works together to plan and provide treatment.

But with all these medical professionals, it's easy to be confused or uncertain about who does what. To learn about important members of the cancer care team (besides the patient), see page 33.

How to work with the cancer care team

Cancer caregivers spend a lot of time and effort helping their loved one. But they may be uncertain how to navigate the health care system or how to communicate effectively during their loved one's medical visits.

Here are a few steps you can take to help you work well with the cancer care team.

1. Ask for your loved one's permission

The first step to work with the cancer care team is a simple one: Ask your loved one's permission to be speak on their behalf and to ask questions. Or perhaps your loved one has already asked you to take this responsibility off their hands.

> **"Caregivers shouldn't have to learn everything through trial and error. Ask for information, resources, and support early. You may not be able to control what cancer brings, but being prepared can make the next step feel less overwhelming."**

Some individuals want their caregiver to take an active part in every conversation. Some don't. Even if you disagree, respect your loved one's decisions—yet be ready to step in, without judgment, if they change their mind later on.

If your loved one agrees, ask about access to their patient portals, medical record, and text messaging.

2. Ask to work with the cancer care team

In addition to getting permission from your loved one, also ask at the cancer center about working with the cancer team. Check with the center's cancer care coordinator or with your loved one's oncologist or primary care provider.

The cancer center can provide your loved one with a Release of Health Information form. This document gives the cancer center permission to provide you with access to your loved one's patient information.

In addition:

- Establish good communication with the cancer care team. Talk with members of the care team, introduce yourself as the caregiver, and ask for their support.
- Make sure your loved one is involved in shared decision-making to the extent they want to be involved.
- Ask which member of the team will coordinate your loved one's care.
- Ask if one member of the team can be your main contact.
- For hands-on aspects of caregiving, ask for educational support, information resources, and training.

3. Be comfortable asking questions

Asking questions is a normal and important part of good health care. Questions help you understand advice, avoid confusion, and make informed choices. Caregivers should feel free to ask for clarification anytime something isn't clear.

Learning to navigate cancer care can be hard, like climbing a steep hill. But you don't have to make the climb alone. Asking questions can help you learn along the way and find the support you need.

Take notes of the answers when you ask questions. Write down who you talked to and when you spoke with them.

Keep a list of names and contact information for each member of the care team. This will make it easier for anyone involved in the care of your loved one to know who to contact with questions or concerns.

4. Get plugged in to technology

Health care communication now happens in many ways other than in-person visits.

Beyond simple phone calls, cancer care communication now includes tools like online patient portals, telehealth visits, automated phone systems, secure messaging, AI chatbots, and remote monitoring.

There are also phone apps that can keep track of medications, send reminders about health care visits, and record daily symptoms.

If using some or all of these technologies is unfamiliar to you and your loved one, ask family members or friends for help. You can also ask the care team for resources to help you learn.

Share observations

You can provide unique insights about your loved one to the care team.

Each member of the cancer care team has their own area of expertise. Your contribution is to offer expert observations about your loved one and share what you observe to the care team.

Why? Because no one else sees and knows your loved one as well as you do.

Caregivers are often the first to notice small changes—like shifts in appetite, energy, sleep, mood, memory, medicine use, or symptoms—before such changes show up at regular clinical visits.

Caregivers can then share what they notice with the care team to provide a better picture of the patient's daily life and behavior.

When caregivers, patients, and health care professionals work together, they can make better decisions and provide more coordinated care.



Caregiver's Corner

Even quick bouts of exercise are good for you and can lower stress.

Play with your pet for a few minutes a day. Do a dozen jumping jacks. Take the stairs. Or just take a walk around the block.

For more self-care tips, see *Chapter 6: Take care of yourself, too.*

Key points

- Treatment decisions should involve an entire team of cancer professionals—doctors, nurses, specialists, and other providers—but the central member of the cancer care team is the patient.
- Shared decision-making means working with the cancer care team to create a plan that fits both your loved one's medical needs and their personal goals and preferences.
- The caregiver often steps in as the loved one's advocate to the cancer care team. An advocate is simply someone who supports or acts on behalf of another.
- The caregiver needs to get their loved one's permission to speak on their behalf. If the loved one says no, the caregiver should respect their decision.
- To be an advocate, a caregiver also needs permission from the loved one to allow the cancer care team to share health information with you, the caregiver. Ask the care team for a form your loved one can complete.
- Ask the cancer care team questions anytime something isn't clear.

Questions to ask your loved one

- Is it okay for the care team to share your medical information with me?
- Who will be the main contact person the cancer care team talks to?
- Which of us will schedule appointments and other visits?
- Is it okay for me to access your patient portal?
- Is there any information you don't want me to share with the cancer care team?

No one else sees and knows your loved one as well as you do.

5

Providing patient care and support

40 Caregivers aren't perfect

41 Organizing medical information

42 Coordinating transportation

42 Managing medications

43 Scheduling social visits

43 Helping with bathing and dressing

43 Helping with toileting

44 Assisting with transferring

44 Managing household responsibilities

45 Dealing with finances

45 Navigating health insurance

46 Preparing for legal matters

47 What comes after caregiving?

48 Key points

48 Questions to ask the cancer care team

As a caregiver, you may help with many practical problems and unexpected events. But that doesn't mean you need to know how to handle everything on your own. Be flexible and remember that you're only one person.

Caregivers often need answers to immediate questions: How do I prepare for appointments, organize medical information, administer medications, or change a catheter bag? These practical concerns require clear directions.

This chapter covers some of these concerns, but know that you don't need every answer right from the start.

Instead, think of caregiving as a process—one where you learn, grow, ask questions, accept help, and build confidence over time.

Being flexible and ready to adapt to unexpected challenges is more important than providing "perfect" care.

Think ahead about how you'll handle unexpected situations. Knowing emergency contact numbers, keeping important documents handy, updating medication lists, and talking through backup plans with the health care team can help you feel more confident during stressful moments.

"As caregivers, we stand as both witness and advocate, learning, questioning, speaking up. We hold hope in one hand and honesty in the other, making room for every small joy. In the time we share, we choose presence, love and dignity."



Caregivers aren’t perfect

Many caregivers put huge pressure on themselves. They worry about making mistakes, saying the wrong thing, or failing to do something their loved one needs.

But no caregiver can predict every challenge. Sudden changes, treatment delays, hospital stays, side effects, and shifting priorities are all common parts of the cancer journey.

As a result, stress runs high, and feelings of guilt and self-doubt are common—especially since caregivers are often juggling multiple responsibilities alongside caregiving, including work and parenting.

At the same time, caregivers often deal with uncertainty, changing relationships, emotional exhaustion, grief, shifting family roles, and worries about their own well-being.

But caregivers don’t need to be perfect to provide meaningful support. Compassion, willingness to learn, and asking for help when needed are qualities that go a long way.

The information in this chapter won't erase your self-doubts. But it can help you build a system that makes daily life easier—so you can save your time and energy for what matters most: caring for your loved one.

One task that can make life more manageable is organizing all the medical information that comes your way.

“Your role as a caregiver did not come with a playbook. But you showed up in unexpected ways throughout our journey and became an integral part of our recovery.”



Organizing medical information

Medical appointments for cancer care generate a significant amount of information and documents.

Medical information

Appointment schedules, lab results, medication lists, imaging reports, insurance statements, and contact information can pile up fast.

Caregivers often end up managing all this information, especially when several doctors or medical centers are involved.

Organizing it all might feel overwhelming at first, but doing so can lower your stress and save time later.

You don't need anything fancy to be organized. Use whatever works for you—a notebook, binder, calendar, app, flash drive, or a secure folder in the cloud. What matters most is being able to find information quickly, not having a complex system.

Appointment information

Health care visits often pack a lot of information into a short time. Stress and worry about your loved one can make it hard for both you and your loved to remember everything you talked about.

Prepare ahead for the visit by writing down your questions, bringing an updated medication list, noting any symptoms or concerns, and knowing your top priorities. This helps you communicate better and can make you feel more confident during appointments.

Again, simple tools—notebooks, apps, calendars, or binders—can help you keep track of everything without having to remember it all yourself.

Keep a binder or folder of information. Keep all phone numbers in one place.

If your loved one wakes up ill at midnight, it's after hours and you need to know who to call. Be prepared before that happens, so you have what you need when you need it.



Coordinating transportation

Transportation often becomes a major part of caregiving. Frequent appointments, treatments, imaging scans, lab visits, and unexpected health needs require a lot of coordination. Driving to the grocery store, pharmacy, place of worship, or running errands adds even more to the load.

Plan ahead when you can—confirm appointment times, leave extra time for delays, and have backup transportation options in mind. Also allow extra time for getting out of the car, finding the right office, and a possible bathroom break.

Giving rides can be one specific task that other friends or family can do. It can even be a way that other helpers can enjoy one-on-one time with the loved one. Keep in mind that transportation challenges are different depending on whether you're in an urban, suburban, or rural area.

Ask the social worker or another member of the care team about what help is available. Also seek local resources that offer transportation.

Managing medications

Cancer medications need to be taken correctly—the right drug, the right dose, at the right time. This matters for caregivers because medication schedules often get more complicated as the cancer journey goes on. Managing multiple prescriptions with varying dosages, supportive medications, and over-the-counter products takes careful coordination.

Here are some key tips:

- Keep an updated list of all medications.
- Know what each medication is for.
- Ask about possible drug interactions.
- Ask if pills can be cut or crushed before doing so on your own.
- Know who to contact with questions about side effects or missed doses.
- Keep the pharmacy name, address, and phone number available.
- Know when refills are needed.

Simple tools—like medication logs, pill organizers, or electronic reminders—can help cut down on mistakes while boosting your confidence.

For convenience, ask if the pharmacy offers delivery by mail or to your door.

Administering injections

More than half of all caregivers (55%) do medical or nursing tasks that are usually handled by health care professionals—but few caregivers (22%) are trained to do them, according to *Caregiving in the US 2025*.

Tasks for some caregivers include giving injections or caring for a feeding tube or a central line. A central line is a thin tube placed into a large vein in the chest or neck, making it easier to give medications regularly. It stays in place for weeks or months and needs regular cleaning.

If no one shows you how to do these tasks, don't hesitate to ask the cancer care team to teach you how to do them.

Scheduling social visits

You may not think of yourself as an event planner, but scheduling social visits and outings can help your loved one (and you) avoid feeling lonely, depressed, and isolated.

Sometimes, just getting out of the house for an errand or a short excursion can be a refreshing change of pace.

- **Plan** in-person visits with friends, family, neighbors, and coworkers. Avoid times when your loved one's immune system is low.
- **Assist** with FaceTime, Zoom, or another video communication tool.
- **Sign** your loved one up for a class or enroll in one together. Look for activities they would enjoy, such as a book club, a knitting group, or even water aerobics.

Helping with bathing and dressing

Your loved one may need assistance with bathing or dressing.

But it can feel awkward for both you and your loved one if they need help in the bath or shower. It could also be physically awkward—even dangerous—without safety measures in place.

If your loved one needs help with bathing, the tub or shower should be accessible. If it isn't, installing grab bars and a non-slip bathmat or adding a shower chair or a tub transfer bench can increase physical comfort and safety.



Apps that track medications

- EveryDose
- Medisafe
- Pillbox
- Pill Reminder

Take similar safety measures—having a chair or a grab bar for support—when helping your loved one change clothes.

Helping with toileting

Similar to bathing, take safety measures in the bathroom by installing grab bars or an elevated toilet seat if your loved one is in danger of falling or slipping off the toilet.

Urinary incontinence

A common problem for people with cancer is urinary incontinence—loss of control over urination. Urinary incontinence isn't normally a part of aging. However, it can be due to the cancer itself—particularly prostate, bladder, or uterine cancer—or to the side effects of certain cancer treatments.

When it's due to cancer or cancer treatment, incontinence is often a temporary problem and tends to get better over time. Meantime, help

your loved one keep wetness under control with protective underwear or absorbent pads.

Treatment for incontinence is possible, and includes pelvic floor exercises (Kegels), bladder training, medication, or surgery, depending on the root cause of the problem.

Managing catheters

A urinary catheter is a thin plastic tube inserted into the opening (urethra) of the penis or vagina to allow urine to drain out. Some patients need a catheter temporarily while they're healing after surgery or other treatment.

The catheter may be inserted elsewhere on the abdomen, such as in the case of bladder surgery, and drains into a flat plastic pouch called an ostomy bag. The urine is held for a short time until the ostomy bag can be emptied.

You may need to assist your loved one with emptying or changing the pouch and cleaning the catheter tube. Ask the cancer care team to show you exactly how to do it and also request printed instructions that you can take home. Ask who you should contact if you have questions, including after hours.

Assisting with transferring

Transferring your loved one from a bed to a wheelchair (or vice versa) can put you both at risk for injury.

This guide can't cover every technique for safe transfers, but you can ask the cancer care team if a physical or occupational therapist can evaluate your loved one's needs and provide training for you.

"Ask about clinical trials available and the services your hospital and other facilities provide to cancer patients, such as counseling, nutritional advice, meditation, physical therapy, palliative care, and integrative medicine."

Many local hospitals and home health care services also train caregivers to safely care for a loved one at home. Or outside services can be hired if needed.

Managing household responsibilities

Daily household tasks don't stop just because someone develops cancer.

Cooking, cleaning, grocery shopping, laundry, childcare, pet care, paying bills, and housekeeping can become hard to manage alone.

If you're feeling stretched thin, try prioritizing. Some tasks can be simplified, postponed, delegated, or shared with family, friends, neighbors, or even community groups.

Separating what's essential from what can wait can help reduce unnecessary stress and feelings of inadequacy.

Dealing with finances

Money worries are common during cancer treatment, no matter one's income level. Medical bills, transportation, loss of employment or work reduction, health insurance, and prescription medicines are costs that add up fast. So it helps to plan ahead financially.

Some basic tips to consider:

- Make a list of your loved one's income and assets (bank accounts, property, investments, retirement funds, etc.)
- Write down all recurring bills and expenses
- Set up financial power of attorney to allow you to pay the bills, if needed
- Sign up for automatic bill payments

Help your loved one make a budget. If you don't have one either, consider making one for yourself—caregiving can affect your income and expenses, too.

This guide can't cover every detail of financial planning, so get help early from a financial counselor, social worker, patient navigator, insurance expert, or local organization before problems pile up.

For example, ask a social worker or another care team member about financial assistance programs your loved one may qualify for. Help may be available for treatment costs, lost income, transportation, living expenses, and prescriptions.

Navigating health insurance

Health insurance can be confusing, but here are some simple tips:

- Check your loved one's insurance policy to see what services and medications are covered.
- Request a case manager from the insurance company. A case manager can answer questions about claims and coverage. It helps to have one specific person to talk to at the insurance company. You can also get insurance help from some of the organizations listed in *Chapter 7: Other resources*.
- Keep copies of all claims and paperwork, organized by category. Also write down notes from phone calls with the health insurer. Include the date, who you spoke to, and what was said.
- If a treatment or procedure is denied, you can challenge that decision. For example, if it's denied for not being medically necessary, you can file an appeal.
- Keep records of the names and contact information from any insurance agents or claims reviewers you speak with.
- If a particular drug isn't covered, ask your loved one's doctor to submit a letter of medical necessity.

Preparing for legal matters

Start discussions about legal matters early.

Talking about serious illnesses and end-of-life issues is difficult. But discussing these concerns in advance can make things easier. Having decisions in place can reduce stress and worry for your loved one and you.

This is called advance care planning.

Advance care planning

Advance care planning means deciding what you would want if you become unable to make medical decisions for yourself. Advance care planning is for everyone, not just for people who are very sick.

The focus is on your loved one receiving the best possible care and making sure their wishes are understood and respected. People with cancer can set up an advance care plan early to help them feel less stressed and better able to cope with their condition.

Advance care planning starts with your loved one having an open and honest discussion with you, the caregiver, as well as the cancer care team and family or friends. This discussion should focus on the coming months and years and the medications or therapies that may give your loved one the best quality of life.

Loved ones should make their wishes known. It's important that everyone clearly understands the goals of their care and their personal wishes about what should—and should not—be done.

Keep all your legal records in an accessible location and format.

Your loved one can decide if there's a point where they might want to stop cancer treatment. They can also decide what treatments they would want for symptom relief.

An advance care plan can also include the patient's wishes for what happens after they die, such as organ donation and funeral arrangements.

Advance directive

Once your loved one has made these decisions, they'll fill out a legal document that explains what they want done if they aren't able to tell the care team themselves. This document is called an advance directive.

An advance directive allows the loved one to authorize their caregiver or someone else to make medical decisions on their behalf (a health care proxy).

Health care providers are required to follow the instructions in an advance directive when a patient is unable to make their own decisions about care.

Your loved one should tell the care team and family about the advance directive and its contents. If family members disagree with the plan, your loved one can speak to members of the cancer care team, such as oncology social workers or palliative care providers. They can help your loved one navigate these difficult conversations.

Your loved one can change the advance care plan at any time. Talking often with the care team can help.

Make sure every doctor on the cancer care team receives a copy of the advance directive to get the document into the medical record.

Power of attorney

One type of advance directive appoints power of attorney for health care or financial decisions. Power of attorney names a person (like a caregiver) who acts on someone else's behalf (like a loved one).

Power of attorney for finances assigns someone the patient chooses to make financial decisions on their behalf. For example, the person with power of attorney for finances can pay bills out of the loved one's checking account.

Power of attorney for health care names someone the patient chooses to make health care decisions on their behalf, including end-of-life decisions. This person is called a health care proxy.

As with any advance directive, make sure to give copies to members of the cancer care team.



Caregiver's Corner

Be careful when lifting heavy loads or transferring your loved one from chair to bed.

Take care of your back and your back will take care of you.

For more self-care tips, see *Chapter 6: Take care of yourself, too.*

What comes after caregiving?

The caregiving journey changes over time. Sometimes treatment ends, and the person you cared for becomes more independent. Other times, cancer must be managed for many years.

Sometimes cancer returns or progresses, and caregiving responsibilities increase or change. Sometimes the loved one dies. Each situation also brings a transition for you, the caregiver.

You might face new routines, rethink responsibilities, return to work or relationships, or wonder what's next. You may feel relief, gratitude, sadness, uncertainty, grief, or hope—even all at once. There is no right way to feel.

As your caregiving role evolves, remember you're still your own person. The strengths, knowledge, experiences, and relationships you gained while caregiving stay with you, but they don't have to define your future.

Keep relying on support—your family, friends, health care providers, counselors, clergy members, caregiver or bereavement groups, and other community resources.

There's no set timeline for adjusting to what comes next. Give yourself the same patience, compassion, and grace that you gave the person you care for. Your journey matters, too.

Key points

- Realize that being a caregiver doesn't mean doing everything perfectly.
- Use a simple system you like for organizing information.
- Prepare ahead for office visits.
- Simple tools for organizing medicines can help cut down on mistakes while boosting your confidence.
- Take safety measures to help your loved one take a shower, get dressed, and use the toilet.
- Ask a social worker or another care team member about financial assistance programs your loved one may qualify for.
- Have discussions about legal matters early, while your loved one is capable of making their own decisions.

Questions to ask the cancer care team

- Do you have any advice for managing multiple medications?
- Who can teach me how to do tasks like giving injections, replacing a catheter, or assisting with transferring?
- What medicines or treatments are available for incontinence?
- Who should we speak with about medical bills and insurance coverage?
- Should any specific treatments be excluded or included in the advance directive?

6
Take care of yourself, too

50 How self-attention slips away

51 What is self-care?

52 Take a break

52 Stay active

53 Give it a rest

53 Eat for health

53 Keep your friends close

54 Hire outside help

54 Get help with work

54 Seek support

55 Recognize your grief

56 Key points

56 Questions to ask yourself

Self-care is not selfish. You can't take care of someone else if you're not taking care of yourself. Here are some quick tips to take good care of you.

In caregiving, the focus is naturally on the person with cancer. But this leads many people—including health care professionals and even caregivers themselves—to overlook the health and well-being of the caregiver.

How self-attention slips away

The loved one's needs are important. As treatment continues and responsibilities grow, caregivers often spend more time and energy caring for their loved one.

This also means caregivers have less time for themselves, often with little chance to look after their own physical, emotional, or social well-being.

Caregivers don't intend to neglect themselves—it happens gradually. The patient's needs slowly take the place of the time caregivers once used to take care of themselves. Skipping breakfast occasionally turns into never eating breakfast. One night of poor sleep becomes the norm. Exercise gets postponed until there's no time left for it.

These changes might feel temporary at first, but caregiving without taking care of yourself can lead to burnout. See **Guide 5**.

These struggles don't affect just the caregiver—they can also impact how well and how long they're able to keep providing care for their loved one.

Self-care is anything you intentionally do for your physical, mental, emotional, or spiritual health.



It's also important to know that many caregivers have these feelings. If this includes you, don't hesitate to get help from a doctor, counselor, social worker, spiritual care advisor, or mental health specialist.

Asking for help shows wisdom and self-awareness, not failure or weakness.

What is self-care?

Self-care is anything you intentionally do for your physical, mental, emotional, or spiritual health.

Caregivers need to know that self-care is not selfish.

Nor is self-care just another task on your to-do list.

Rather, self-care is a key component of caring for someone else. Taking care of your own health, stamina, and sense of self helps you keep going throughout your loved one's cancer journey.

In fact, taking care of yourself is important whether or not you're caring for someone else.

Also, self-care is different for everyone. What helps one caregiver recharge might not work for another. Find realistic, sustainable habits that fit your own life, rather than chasing a perfect balance that may not be possible.

Guide 5
Common signs of caregiver stress

Physical signs	• Exhaustion • Problems sleeping • Changes in appetite • Headaches or body pains • Frequent colds (due to a weakened immune system)
Psychological signs	• Difficulty concentrating • Anxiety • Depression • Loss of interest in previously enjoyable activities • Substance misuse or abuse • Inability to perform daily responsibilities
Emotional signs	• Feelings of helplessness • Thoughts of self-harm • Resenting your loved one

Protect your health and identity

Some caregivers start to see themselves only as caregivers. Over time, they have less and less time for their own interests and activities.

Remember that caregiving is a big part of your life, but it's not all that you are.

Try to keep up with your hobbies, traditions, spiritual practices, creative pursuits, or career goals when you can. Doing so helps you hold onto your sense of self throughout your loved one's cancer journey.

Also continue to take care of yourself by making regular health care visits to your primary care doctor, eye doctor, and dentist.

Take a break

Do something just for yourself, even if it doesn't take much time.

Practice yoga or deep-breathing exercises (which can also lower stress). Call a friend. Read a book. Go see a movie. Get a massage. Take a knitting class. Whatever it may be, take a break to do something you enjoy.

Stay active

Try to set aside time for physical activity whenever possible. Exercise can reduce stress and lower blood pressure. Include your loved one, if possible, so you can both benefit.

Staying active doesn't always mean going to the gym. You can do simple activities, too. Walk to the store instead of driving. Go line dancing. Go bowling. Try pickleball. Walk the dog. Take a hike. Or take the stairs.

Staying active doesn't require intense workouts. Simple activities like taking a walk or playing with your dog can be enough.



Give it a rest

Most adults need 7 to 9 hours of sleep each night to maintain their physical health, brain function, and overall well-being.

A short night's sleep once in a while isn't harmful. However, not getting enough regular, uninterrupted sleep can lead to irritability, stress, high blood pressure, impaired mental function, and other problems.

Some simple ways to improve sleep:

- Try to keep a consistent bedtime. Go to bed and wake up at the same time every day, including weekends.
- Calm your environment. Make your bedroom cool, dark, and quiet.
- Use your bed for rest. Keep phones, work, and homework out of bed.
- Avoid naps and caffeine after mid-afternoon.

Eat for health

When you're busy, it's normal to reach for quick or ready-made processed food. But vegetables, fruits, beans, fish, chicken, and whole grains are still the best choices for a healthy diet. They also help your mood and mental health.

And remember to stay hydrated by drinking plenty of fluids throughout the day.

If you're cooking for yourself and your loved one, focus on foods with protein (which helps the body heal), along with vegetables, fruits, and whole grains.



Taking care of yourself is important whether or not you're caring for someone else."

Cook food thoroughly and refrigerate leftovers soon after cooking to avoid food poisoning, which can be especially dangerous for people with weakened immunity.

Lastly, if cooking helps you relax, enjoy it!

Keep your friends close

Cancer doesn't just affect your relationship with your loved one. It can also affect your relationships with family members, friends, coworkers, and people in your community.

Caregivers may slowly pull away from social situations due to lack of time, emotional exhaustion, or just not knowing what to say. But maintaining relationships provides emotional support, perspective, and a reminder that life goes on beyond illness.

Stay connected to people and activities that bring enjoyment and give you a sense of belonging. Even small moments of connection help boost your resilience.

Hire outside help

Respite care gives caregivers a temporary break while someone else looks after their loved one.

Respite care can take place at home or outside the home at a hospital, nursing home, adult day care center, or assisted living facility.

Respite care may come from informal sources, like volunteers or faith-based groups. It can also come from professional agencies with trained (and sometimes licensed) caregivers. These usually require out-of-pocket payment.

The ARCH National Respite Network (archrespite.org) has a national database of respite programs and other resources to help you find respite care near you.

Get help with work

Seven out of 10 caregivers have a job in addition to caring for a loved one. For at least half of caregivers, caregiving affects their work due to arriving late, leaving early, or taking time off to provide care.

If you're balancing work and caregiving, contact your human resources department for support. Options may include paid or unpaid family leave, paid sick days, flexible hours, employee assistance programs, or working from home.

"You have permission to ask for help and support for you, too. While you are not the person going through the disease, it still impacts you in ways you may not even realize."

Seek support

Many caregivers find support groups to be helpful. Support groups often include caregivers at different stages of the cancer journey.

Contact your cancer care team to get in touch with a social worker or counselor who can discuss what resources, such as support groups, are available to you.

Also check your community organizations and look at the national organizations listed on pages 58–59.

Recognize your grief

Grief isn't only for when someone dies. You can also grieve the loss of a job, the end of a marriage, even kids going off to college.

You and your loved one may both be grieving the lives you had before cancer or grieving the future you had planned. Or you may be grieving the person your loved one used to be before cancer changed things.

It's important to acknowledge grief—it might feel like sadness, anger, or irritability. Give yourself time to feel these emotions. If you don't take time to process grief, it could come out in unexpected ways.

Seek help from a mental health professional, therapist, counselor, or social worker. You could also join a support group.

"Remember to take care of yourself. You can't take care of your loved one if you are running on empty."

Accept your emotions

Caregiving is challenging. Give yourself permission to feel your emotions, including guilt, shame, loneliness, resentment, envy, or anger.

Find healthy ways to express or talk about your feelings. Let those feelings out (at the right time and place). Consider talking with a mental health professional, therapist, counselor, or social worker.

Consider joining a support group for caregivers.

Talking with other people who are or have been caregivers can be informative and reassuring.



Key points

- The health and well-being of caregivers is often overlooked, including by caregivers themselves.
- Changes to your personal life might feel temporary at first, but caregiving without taking care of yourself can lead to burnout.
- Get help from a doctor, counselor, social worker, spiritual care advisor, or mental health specialist if these feelings become overwhelming.
- Do something just for yourself, even if it doesn't take much time.
- Get enough regular sleep each night to maintain your physical health, brain function, and overall well-being.
- Maintaining personal relationships provides emotional support, perspective, and a reminder that life goes on beyond illness.
- If you're feeling grief, it's important to recognize it and seek help if you need it.

Questions to ask yourself

- Do I have signs of caregiver stress? Who can I talk to about it?
- Am I doing something just for myself every day?
- What physical activity would be easy for me to do between other responsibilities?
- When was the last time I had a night out with friends?
- Am I bottling up my feelings? How can I safely let them out?



Caregiver's Corner

It's important to look after the health of your loved one. But what about your own health?

Remember to make regular visits to see your primary care provider, dentist, eye doctor, or other providers.

7
Other resources

58 What else to know

58 What else to do

58 Where to get help

59 Questions to ask the cancer care team

Want to learn more? Here's how you can get additional help.

What else to know

This guide helps you know your options so you can make informed decisions and improve the care you provide for your loved one. But it's not the only resource that you have.

Ask for as much information and help as you need. Many caregivers are interested in learning more about:

- The details of their loved one's cancer and its treatment
- Working with the cancer care team
- Getting others to help with caregiving
- Finding a mental health professional, counselor, or therapist to talk to
- Coping with exhaustion and difficult emotions

What else to do

Your loved one's health care center can help you with additional steps. It often has on-site resources to help meet your needs and find answers to your questions. Health care centers can also inform you of resources in your community.

In addition to help from the cancer care team, the resources listed in the next section provide support for many caregivers like yourself.

Where to get help

Look through the list below and visit the provided websites to learn more about these organizations.

AnCan Foundation
ancan.org

Aplastic Anemia & MDS International Foundation
aamds.org

Bladder Cancer Advocacy Network
bcan.org

Blood Cancer United
bloodcancerunited.org

Cancer*Care*
cancercare.org

Cancer Active, Inc.
becanceractive.org

Cancer Nation
canceradvocacy.org

Cancer Support Community
cancersupportcommunity.org

Cancer Survivor Care
cancersurvivorcare.org

Cholangiocarcinoma Foundation
cholangiocarcinoma.org

Clear Cell Sarcoma Foundation
clearcellsarcoma.org

CML Buster Foundation
cmlbf.org

Cutaneous Lymphoma Foundation
clfoundation.org

DiepC Journey Foundation
diepcfoundation.org

GRACE
cancergrace.org

Histiocytosis Association
histio.org

Imerman Angels
imermanangels.org

Leukemia Research Foundation
leukemiarf.org

Lung Cancer Initiative
lungcancerinitiative.org

Mucinous Ovarian Cancer Coalition
hope4moc.org

NMDP
nmdp.org

Ovarian Cancer Research Alliance
ocrahope.org

Pancreatic Cancer Action Network (PanCAN)
pancan.org

Patient Empowerment Network
powerfulpatients.org

Prostate Health Education Network (PHEN)
prostatehealthed.org

Stupid Cancer
stupidcancer.org

THANC Foundation
thancfoundation.org

The Multiple Myeloma Research Foundation
themmrf.org

Triage Cancer
triagecancer.org

Questions to ask the cancer care team

- Who should we contact after hours or in an emergency?
- Where can we get a second opinion?
- What kind of financial assistance or support services are available to us?
- Is there an appropriate clinical trial my loved one can join?
- What should we do after treatment ends?



Words to know

advance care planning
Making decisions now about the care you would want to receive if you become unable to make medical decisions or to speak for yourself.

advocate
Someone who supports or acts on behalf of another.

biopsy
A procedure that removes tissue samples from the body to be tested for a disease.

caregiver
A person who provides regular care or help to a loved one with cancer.

chemotherapy
A drug treatment that damages and destroys rapidly dividing cells throughout the body.

clinical trial
A research study that assesses how well tests or treatments work in people.

diagnosis
Identification of an illness or disease based on tests.

immunotherapy
A type of treatment that uses the immune system to fight cancer.

metastasis
The spread of cancer cells from where the cancer started to another part of the body.

progression
When cancer continues to grow or spread after treatment.

radiation therapy
Treatment that uses high-energy rays (radiation) to kill cancer cells.

recurrence
Return of cancer after a period of improvement.

remission
Absence of clinical evidence of cancer after treatment.

self-care
Caring for one's own physical, mental, emotional, or spiritual health.

side effect
An unhealthy or unpleasant physical or emotional response to treatment.

supportive care
Health care for relieving cancer symptoms and the side effects of cancer treatment. Also called palliative care.

targeted therapy
A type of treatment that targets a specific or unique feature of cancer cells.

NCCN Contributors

This patient guide was developed, reviewed, and published with help from the following people:

Dorothy A. Shead, MS
Assistant Vice President
Patient Information Operations

John Murphy
Senior Medical Writer

Lisa Diehl
Production Layout Artist

Susan Kidney
Senior Graphic Design Specialist

The following NCCN Panel Members and collaborators significantly contributed to the development of this patient guide:

Sarah Conning, MSW, LCSW, OSW-C, APHSW-C
UC Davis Comprehensive Cancer Center

Julie Dalla Rosa, LCSW, OSW-C
The UChicago Medicine Comprehensive Cancer Center

Julie DeBord, MSW, LISW-S
The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

Aïcha Diallo, MPH, CHES
Patient Empowerment Network

Efrat Dotan, MD
Abramson Cancer Center at the University of Pennsylvania

Anthea A. Gray, PsyD
The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

Louise Knight, MSW, LCSW-C, OSW-C
Johns Hopkins Kimmel Cancer Center

Heather Kopecky, PhD, MBA, PCC
Kopecky Leadership Group

Yadira Montoya, MSPH
National Alliance for Caregiving

Larissa Nekhlyudov, MD, MPH
Dana-Farber Cancer Institute

Megan N. Ober, MS, RN, OCN
UC Davis Comprehensive Cancer Center

Belinda Paulicin, DSW, LCSW, OSW-C
Cancer Support Community

JoAnne Rufo, MSW, LSW, OSW-C
Fox Chase Cancer Center

For disclosures, visit NCCN.org/disclosures.

NCCN Cancer Centers

For contact information, visit NCCN.org/cancercenters.

Abramson Cancer Center
at the University of Pennsylvania
Philadelphia, Pennsylvania

Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer Center and
Cleveland Clinic Taussig Cancer Institute
Cleveland, Ohio

City of Hope National Medical Center
Duarte, California

Dana-Farber Cancer Institute
Boston, Massachusetts

Duke Cancer Institute
Durham, North Carolina

Fox Chase Cancer Center
Philadelphia, Pennsylvania

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska

Fred Hutchinson Cancer Center
Seattle, Washington

Huntsman Cancer Institute at the University of Utah
Salt Lake City, Utah

Indiana University Melvin and Bren Simon
Comprehensive Cancer Center
Indianapolis, Indiana

Johns Hopkins Kimmel Cancer Center
Baltimore, Maryland

Mass General Brigham Cancer Institute
Boston, Massachusetts

Mayo Clinic Comprehensive Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota

Memorial Sloan Kettering Cancer Center
New York, New York

Moffitt Cancer Center
Tampa, Florida

O'Neal Comprehensive Cancer Center at UAB
Birmingham, Alabama

Robert H. Lurie Comprehensive Cancer Center
of Northwestern University
Chicago, Illinois

Roswell Park Comprehensive Cancer Center
Buffalo, New York

Siteman Cancer Center at Barnes-Jewish Hospital
and WashU Medicine
St. Louis, Missouri

St. Jude Children's Research Hospital/
The University of Tennessee Health Science Center
Memphis, Tennessee

Stanford Cancer Institute
Stanford, California

The Ohio State University Comprehensive Cancer Center -
James Cancer Hospital and Solove Research Institute
Columbus, Ohio

The UChicago Medicine Comprehensive Cancer Center
Chicago, Illinois

The University of Texas MD Anderson Cancer Center
Houston, Texas

UC Davis Comprehensive Cancer Center
Sacramento, California

UC San Diego Moores Cancer Center
La Jolla, California

UCLA Jonsson Comprehensive Cancer Center
Los Angeles, California

UCSF Helen Diller Family Comprehensive Cancer Center
San Francisco, California

University of Colorado Cancer Center
Aurora, Colorado

University of Michigan Rogel Cancer Center
Ann Arbor, Michigan

University of Wisconsin Carbone Cancer Center
Madison, Wisconsin

UT Southwestern Simmons
Comprehensive Cancer Center
Dallas, Texas

Vanderbilt-Ingram Cancer Center
Nashville, Tennessee

Yale Cancer Center/Smilow Cancer Hospital
New Haven, Connecticut

Index

advance care planning 46

advance directive 46–47

advocate 32, 34

biopsy 14

cancer care team 33, 34–35

caregiver 5–9, 19, 23, 25, 28, 32, 36, 40, 44, 56

catheter 44

chemotherapy 15–17

clinical trial 15–16

diagnosis 14

immunotherapy 15–17

incontinence 34–35

metastasis 13

progression 19

radiation therapy 15–17

recurrence 19

remission 18

self-care 51–52

supportive care 16, 18

suvivorship 19

targeted therapy 15–17

transferring 44

transportation 42



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.
NCCN.org/patients/response



NCCN Guidelines for Patients®

Cancer care recommendations from leading experts at the
National Comprehensive Cancer Network® (NCCN®)

Caregiving for People With Cancer



The way forward starts here.

Give Now

National Comprehensive Cancer Network® Foundation

National Comprehensive Cancer Network®

3025 Chemical Road, Suite 100
Plymouth Meeting, PA 19462
215.690.0300

NCCN.org/patients – For Patients | NCCN.org – For Clinicians

PAT-N-1998-1226