

Paths to Survivorship™

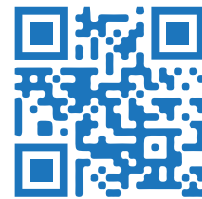
Support and reliable information to help you with a cancer diagnosis and beyond



Bag It Cancer is a national nonprofit whose mission is to educate, support and empower those impacted by cancer. Since 2003, we have provided people with any type of cancer with reliable information, tools, and resources—right when they need it most.



BagItCancer.org



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Paths to Survivorship

We know that a cancer diagnosis can be overwhelming. That's why **Bag It** compiled reliable information from leading cancer organizations to create **Paths to Survivorship**. This guide was designed to help you and those around you understand cancer and manage the challenges of diagnosis, treatment, and every phase of survivorship.

Every cancer is different, and every person is impacted by cancer differently, so we've included a lot of information covering many topics. Look over the sections that you need now and read other parts later when they interest you. Feel free to mark up the pages. Bookmark the pages that are especially helpful and something you want to read again or share.

Paths to Survivorship can assist you in becoming more knowledgeable about cancer and advocating for yourself to receive the care and support you need to live your best life possible with cancer.



You are a **cancer survivor**—regardless if you were diagnosed today or decades ago.

Bag It chose to use **cancer survivor** in this booklet to refer to someone who has had a diagnosis of cancer, no matter the stage or prognosis, until the end of life. This term might mean something different to you. You may not relate to or be comfortable with this term now or ever. You may prefer other words along the way, or none at all. The choice is yours.

The National Coalition for Cancer Survivorship (NCCS) defines Survivorship as the process of living with, through, and beyond a cancer diagnosis.

The booklet has scannable QR codes that link to our website for print versions of: questions to ask, checklists, and self-advocacy tips.

Visit BagItCancer.org for more cancer resources. You can also download the PDF format of this booklet to email to someone else.

Complete the feedback form in *My Companion Guidebook* or online: BagItCancer.org/feedback

Scan to complete online



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Self-Advocacy and Your Cancer Care

*“It is the greatest of all mistakes to do nothing
because you can only do a little.
Do what you can.”*

- Sydney Smith



What is self-advocacy?

Self-advocacy in cancer care can be described as taking actions to gather the information, tools and skills needed to feel confident, knowledgeable and comfortable in speaking up for yourself to your healthcare team and others around you. This includes communicating, negotiating, and problem-solving, being an active part of your healthcare team, making informed choices about your care, and expressing your needs and preferences to get the support you want.

Why is self-advocacy important?

Imagine the actions you might take to help a family member or close friend dealing with a serious illness, or how you would stand up for a child struggling in school. Being that someone in their corner can go far to make sure they receive the support they need. You deserve no less.

Advocating for yourself can lead to higher quality healthcare, a better quality of life, and possibly a better outcome. By being an informed and proactive member of your healthcare team, you will be more equipped to make sound decisions about your treatment and care. Having the skills to confidently express yourself well and be understood by others is key to make sure you receive the care and support you want and are entitled to. You may feel more in the driver's seat, more stable, more hopeful, and better able to cope.

How do I advocate for myself?

The next page offers tips on how to be a self-advocate from the day of diagnosis and for the rest of your life.

This booklet and the others in your **Bag It** bag arm you with cancer information and resources you can use and trust. The bag is filled with tools and suggestions on how to be actively involved in your care and the decision-making process, working side-by-side with your healthcare team and a support team of your choosing. It helps you build the communication, negotiation and problem-solving skills required for you to give voice to your needs and preferences, in all areas of your life.

If speaking up for yourself is too difficult or stressful for you, ask a family member or friend for help at the beginning. Then try a few steps on your own to feel more confident advocating for yourself. It might feel awkward at first, but it usually gets easier over time.

Another option is to consider the services of a volunteer or hired patient advocate or navigator. Having someone advocate on your behalf when you are not up to the task is a sign of strength, not weakness. Ask your healthcare team what resources are available to you.

Tips for Self-Advocacy

<h2>Get Informed</h2> <ul style="list-style-type: none">• Learn from reputable sources so you can speak knowledgeably and make sound decisions about your cancer care.• Ask the right questions about your cancer: goals of care, benefits, risks, side effects, and quality of life on treatments.• Understand your health insurance coverage and the cost of your care.• Stay informed along the way.	<h2>Get Organized</h2> <ul style="list-style-type: none">• Get printed copies of your medical records from your healthcare providers, or access them through the online portal to print or save onto your device.• Use <i>My Companion Guidebook</i> to record, store and track your medical info and schedules. Bring it to your appointments.• Prepare for doctor visits. Write your questions and info to share. Bring someone with you (in person or virtually) to help.
<h2>Know Yourself</h2> <ul style="list-style-type: none">• What is important to you?• What are your goals of cancer treatment?• What are your personal hopes, strengths, needs, concerns, and preferences?• What help do you need?• Listen to your body.	<h2>Speak Up</h2> <ul style="list-style-type: none">• Confidently, directly yet kindly, and honestly.• Ask questions until you fully understand the answers.• Voice concerns until you are understood.• Report changes in your physical, emotional and mental well-being.• Know how to ask for the help you want, and accept the help offered.
<h2>Build Your Team</h2> <ul style="list-style-type: none">• Find a cancer care team that is a good fit for you and where you can receive the best quality care possible.• Add support to lean on: family, friends, neighbors, groups in your area.• Connect with others living with cancer. Try a support group, peer mentor, or an online community.	<h2>Know Your Rights and Protections</h2> <p>Under federal, state and local laws:</p> <ul style="list-style-type: none">• As a patient or caregiver.• On the job.• For health and disability insurance.• For benefit(s) eligibility (public/employer).• Related to your finances.• For estate planning.
<h2>Take Action</h2> <ul style="list-style-type: none">• Be an active member of your healthcare team, or find someone you trust to advocate for you.• Ask your doctor for supportive/palliative/home health care and other cancer resources to help you.• Create advance directives no matter your prognosis.• Look into financial resources to help with medical and non-medical expenses.• Plan for “what if” scenarios.	<h2>Decision Making and Problem Solving</h2> <ul style="list-style-type: none">• Communicate, communicate, communicate.• Work with your healthcare team to make informed choices about your care.• Consider getting a second opinion.• Find solutions and negotiate to overcome challenges. Be persistent and follow up.• Ask for input and help from trusted sources along the way.

Survivorship Checklist

Type of cancer: _____ Date: _____

Other info: _____

Treatment

- | | | |
|---|---|---|
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Immunotherapy | <input type="checkbox"/> Supportive/Palliative Care |
| <input type="checkbox"/> Chemo (IV, port, oral) | <input type="checkbox"/> Stem Cell Transplant | <input type="checkbox"/> Physical Therapy |
| <input type="checkbox"/> Radiation Therapy | <input type="checkbox"/> Clinical Trials | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Hormone Therapy | <input type="checkbox"/> Biomarker Testing | <input type="checkbox"/> Other _____ |

Support System

- | | | |
|---|--|---|
| <input type="checkbox"/> Spouse/Partner | <input type="checkbox"/> Neighbors | <input type="checkbox"/> Support Group/Peer Support |
| <input type="checkbox"/> Family | <input type="checkbox"/> Religious/Spiritual Advisor | <input type="checkbox"/> Survivorship Program |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Navigator/Patient Advocate | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Social Worker/Counselor | |

Concerns and Side Effects

- | | | |
|---|--|---|
| <input type="checkbox"/> Physical | <input type="checkbox"/> Genetic Testing | <input type="checkbox"/> Caregiver/Family Support |
| <input type="checkbox"/> Emotional Well-Being | <input type="checkbox"/> Fertility/Sexuality | |

Wellness and Support Activities

- | | | |
|--|---|---|
| <input type="checkbox"/> Healthy Diet | <input type="checkbox"/> Religious Faith/Spirituality | <input type="checkbox"/> Yoga/Tai Chi/Stress Management |
| <input type="checkbox"/> Nutrition Counseling | <input type="checkbox"/> Exercise/Physical Activity | <input type="checkbox"/> Meditation/Relaxation Techniques |
| <input type="checkbox"/> Stopping Smoking | <input type="checkbox"/> Healthy Weight | <input type="checkbox"/> Individual Counseling |
| <input type="checkbox"/> Limit Alcohol | <input type="checkbox"/> Journaling | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Continued Education/
Self-Advocacy | <input type="checkbox"/> Acupuncture/Massage | |
| <input type="checkbox"/> Support Groups/Peer Support | <input type="checkbox"/> Volunteering | |
| | <input type="checkbox"/> LIVESTRONG at the YMCA | |

Practical Matters

- | | |
|---|--|
| <input type="checkbox"/> Life Planning (powers of attorney & wills) | <input type="checkbox"/> Financial (medical costs, household expenses) |
| <input type="checkbox"/> Insurance (health, disability) | <input type="checkbox"/> Practical (child care, meals, in-home care, transportation) |
| <input type="checkbox"/> Work/Legal Rights | |

Ongoing Care/Follow-up Care

- | | |
|--|--|
| <input type="checkbox"/> Extended Treatment _____ | <input type="checkbox"/> Late/Long-Term Side Effects |
| <input type="checkbox"/> Oncology Follow-up Care | <input type="checkbox"/> Physical Therapy |
| <input type="checkbox"/> Supportive/Palliative Care | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Primary Care/Family Physician | <input type="checkbox"/> Treatment Summary & Survivorship Care Plan
(see page 65) |
| <input type="checkbox"/> Care By Specialists | <input type="checkbox"/> Survivorship Program |
| <input type="checkbox"/> Dental Care | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Vision Care | |

[2]

Diagnosis and Treatment

Your Healthcare Team

During the diagnosis phase, you will begin to build your healthcare team to ensure you are receiving the best care and support possible. You are the most important member of the team and all team members will be focused on you. Your oncologist will usually lead the team and refer you to other providers as needed. Be sure to ask questions if you are unsure about a team member's role. If you feel that you may benefit from additional team members, speak to your oncologist or patient advocate. You may have some or all of the following healthcare professionals caring for you at some point or throughout your cancer treatment and beyond.

Surgeon

Surgeons perform procedures and surgeries to diagnose and treat cancer. This may be a general surgeon or one who specializes in a particular cancer surgery. If you are referred to a general surgeon, you can ask for a specialist for your cancer type.

Case manager

Case managers are usually registered nurses or social workers with a particular expertise in care coordination. They ensure that patients have the services they need and that healthcare resources and services are being allocated appropriately. They often work in inpatient (hospital) settings to facilitate discharge planning and serve as a liaison between the patient, family, and medical staff, but can also be found in outpatient clinics, subacute care facilities such as nursing homes, and home health settings.

Medical oncologist

A doctor who has special training in diagnosing and treating cancer in adults using chemotherapy, hormonal therapy, biological therapy, and targeted therapy. A medical oncologist often is the main healthcare provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists, including integrative therapy.



Nurse

A health professional trained to care for people who are ill or disabled. Nurses work in a variety of roles. They are licensed and professionally accredited at the state and often national level. Depending on their certifications and experience, nurses can perform assessments and exams, coordinate care with the cancer team, provide information about your cancer, treatment, potential side effects and how to manage them, monitor and administer treatments like chemotherapy, provide supportive care, and also be involved in clinical trials research.

Oncology nurse practitioner and physician assistant

A healthcare professional with additional education, training, and experience in how to diagnose and treat cancer. As an advanced practice provider, they possess licensing and certification to perform many of the same tasks as a doctor. They typically work jointly with your doctors and may be additional providers during your cancer journey.

Oncology social worker

A professional trained to help people with cancer and their families to cope emotionally through one-on-one counseling and support group/buddy programs. They coordinate with members of your healthcare team, offer tools and practical assistance for day-to-day non-medical challenges, and provide other resources for community and local support services. They may work at the cancer clinic or hospital where you are being treated or are available to help online or by phone through a nonprofit organization, possibly free of charge.

Patient navigator (also called patient advocate)

A person who helps guide a patient through the healthcare system. This includes help going through the screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer. A patient navigator helps patients communicate with their healthcare providers so they get the information they need to make decisions about their healthcare. Patient navigators may help patients set up appointments for doctor visits and medical tests and get financial, legal, and social support. They may also work with insurance companies, employers, case managers, lawyers, and others who may have an effect on a patient's healthcare needs.

Navigators can be licensed nurses, social workers, or laypersons with specialized training and experience. They may work at the cancer clinic or hospital where you are being treated or for your insurance company. Navigators can be volunteers and can also be hired privately by people who want help coordinating their care. Be sure to verify the credentials of navigators not affiliated with a cancer center or reputable organization.

Pharmacist

A health professional with special training in preparing and dispensing prescription drugs. Pharmacists understand how drugs work, how to use them, and their potential side effects.

Radiation oncologist

A doctor who has special training in using radiation therapy to treat cancer. They prescribe radiation therapy and manage its side effects.

Communicating with Your Healthcare Team

Hearing that you or a loved one has cancer is overwhelming and stressful, but there are tips and tools to help you adjust to and deal in the best way possible with this diagnosis. One way to begin is to make sure you and your healthcare team understand each other and that you are an active team member. Everyone is there to work with you, so you need to clearly say what you need from them. By communicating well with your healthcare team, you stand to be as successful as possible in this situation. Some tips to keep in mind:

- **Speak openly and honestly with your team.** They need information from you to make sure your needs are addressed.
- **Make sure your doctor listens and understands your needs and concerns.** Don't be afraid to speak up if you don't think you are being understood. To make sure you've been understood, it is often helpful to repeat back to the doctor what you understood them to say.

- **Ask questions and gather information.** Make sure you understand what was said and that you have the best information to make decisions. (See **Questions to ask your healthcare team** on pages 10 and 21.)
- **Make a plan with your team for your treatment and care.** Getting that plan in writing or electronic form is ideal but not always possible in every situation. Knowing what to expect can help you feel more at ease and able to address issues better as they arise.

Problem-solving with your healthcare team

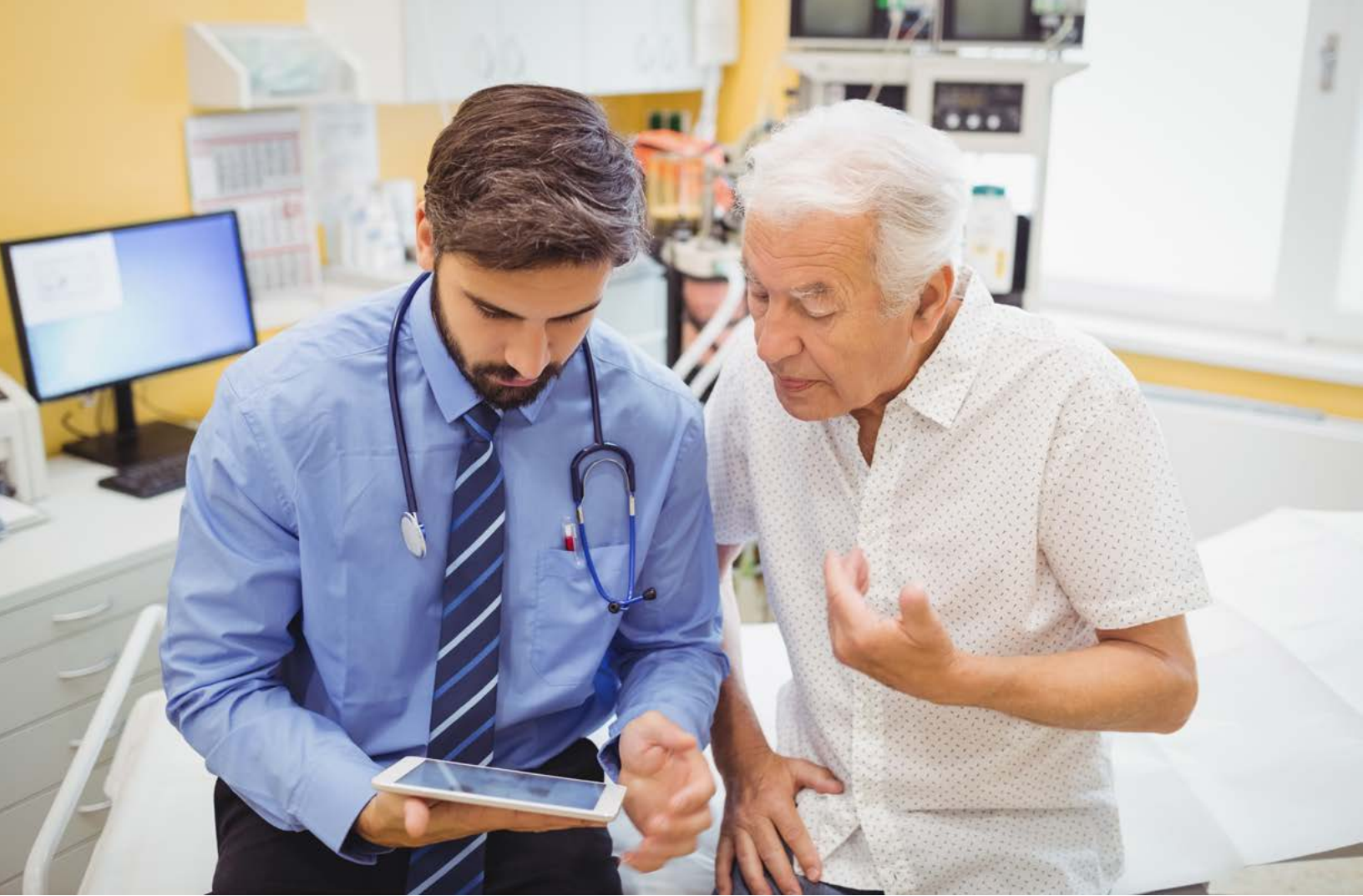
It's important that you feel comfortable with your healthcare team. They have your best interests in mind. Occasionally there is not a good personality fit, there is difficulty communicating, or an issue arises. Part of advocating for yourself is taking steps to problem solve when needed so you feel confident you are getting the best care possible.

- **Share your concerns with a trusted family member or friend.** They may be able to look at the situation more objectively and offer helpful feedback.
- **Have an honest conversation with the person before the matter escalates.** It's possible it can be talked through with a positive outcome.
- If you have a good rapport with someone else on your healthcare team, **express your concerns** to them. They might be able to provide some clarity on the situation, handle the problem directly, or suggest ways to solve it.
- **Sometimes speaking with other cancer survivors** who may have experienced similar situations can offer insight and remedies.
- **If all else fails, it is okay to change healthcare providers.**

Doctors want to know your medical preferences

Some survivors are better able to deal with cancer by leaving most of the information and decision making to their doctor. For these people, having too much knowledge and participating in medical choices is very stressful, and (for them) it may make things more difficult. Others cope by learning all they can about their cancer and its treatment. It is OK to be in either group. Only you know the best way for you to cope. Most survivors are somewhere in between the two categories described above.

Sometimes, the same person may want different amounts of information at different times during their cancer experience. It is important to let your loved ones, doctors, and other team members know how much you want to be informed about your cancer, its treatment, and your health outlook (prognosis). They often look for subtle clues or signals from you. Sometimes they don't know what to do about keeping you informed. Be open with them. Tell them clearly how much information you want. If your needs change, tell them so.



On the other hand, sometimes loved ones may want to know more about the medical treatment and situation than you do. This can put your doctor in the difficult position of needing to safeguard your privacy while being asked by family members for more information. If you're concerned, you have the right to say who should know what kinds of information. You need to make sure your doctor understands your preferences about how much can be discussed with loved ones. You can make it less difficult for them if you discuss these issues and tell your doctor and your loved ones to what extent the doctor has your permission to share information with them.

It might be helpful to choose one person to help you communicate your needs. If you want a family member or friend to help you communicate, discuss this role with that person early on and tell your healthcare team how you want this person involved. Having many people who communicate different messages is confusing and may make it harder to work with your team to make decisions and solve problems.

Questions to ask your healthcare team about your diagnosis

Some of these questions may not apply to you or your cancer, but we hope this list will help you get all the information you need. You may choose to select a few priority questions to ask your doctor or review your list of questions with your oncology nurse or navigator.

1. What is my specific diagnosis?
2. Where is the cancer located? Has it spread?
3. What is the size and stage of my cancer? What are the stages?
4. Are more tests needed at this time to fully diagnose my cancer or determine treatment options?
5. What treatment options do you recommend?
6. What is the duration of each of the treatment options?
7. What are the goals for treatment?
8. Who will be on my healthcare team?
9. What is the best way to reach you for non-urgent questions or concerns?
10. Where can I find information on my diagnosis and treatment? Where can I find support services in my area?
11. Is participation in a clinical trial an option for me? (See **Clinical trials** on page 17.)

Should you learn that you will have long-term treatment or you have advanced cancer, see section 6, **Long-Term Treatment and Advanced Cancer**.

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print version



Helpful Tips

- Bring someone you trust to every appointment (in person, by video call, or by phone) to help you remember information, ask questions, write notes and answers to your questions. Ask the doctor if you can record the visit.
- Use the forms in section 2 of *My Companion Guidebook* to write down your questions for the doctor. Make a copy for them. Be sure to write down the answers you receive.
- Check out the Resources section in *My Companion Guidebook* for reliable websites with information on your cancer type, treatments, and more questions to ask your doctor.
- The National Comprehensive Cancer Network® (NCCN®) offers The NCCN Guidelines for Patients® with specific information about many cancer types. Visit: nccn.org/patients or download the free app.
- You may also find the American Cancer Society ACS CARES™ free app to be helpful.
- See **Questions to ask your healthcare team about cancer treatments** on page 21.

Your Treatment Plan and Goals of Care

Treatment planning is an important early step after your cancer diagnosis, and includes choosing which procedures or medicines you will receive in order to have the best possible outcome. Treatment plans can vary a lot from individual to individual, and may involve multiple appointments with different specialists, or a series of tests before the plan of care can be decided. Your treatment plan will depend upon your individual circumstances and goals of care.

Some individuals have curable disease while others have more advanced cancer, which may not be able to be cured. Goals of care may include: cure, extending life, promoting quality of life, lessening symptoms, or controlling the cancer. Your doctor will help inform your decision making by describing how he or she thinks you will likely respond to treatment, and what the outcomes may be in terms of your health and quality of life. Treatment planning is also a good time to consider getting a second opinion.

During treatment planning, it is important that you continue to advocate for yourself and ask for clarification if you don't understand your doctor's recommendations. Be sure you get the information you need to make informed decisions about your health. Your values and beliefs may impact your treatment choices as well.

Other Considerations at the Time of Diagnosis

Hereditary cancer

You may worry that having cancer could mean your children will get cancer too. Cancer itself is not passed down (inherited) from parents to children. But a genetic change (mutation) that increases the risk (possibility) of cancer can be passed down if it is present in a parent's egg or sperm cells. While most cancer is due to random chance or environmental risk factors, up to 10% of all cancers may be caused by inherited genetic changes. If a person inherits a genetic change from a parent, it does not mean they will definitely get cancer, but the risk is higher. It also means that their parents, children, siblings, and other relatives on that side of the family may have the same genetic change and a higher risk of getting cancer.

Even when there is no gene mutation found in a family, sometimes cancer is more common than expected. This is called familial cancer, and happens in up to 20% of all cancers. It is not known why familial cancers happen. Some possible reasons are unknown genetic risk factors not yet included on genetic testing, or lifestyle or environmental factors shared by multiple family members.

Genetic testing

Genetic testing does not prevent or treat cancer. It does not say if someone has cancer, or that they will definitely be diagnosed with cancer in the future. But having a genetic test when you have cancer can give your doctor information to plan your treatment.

Genetic testing is a laboratory test that looks for changes (mutations) in a person's genes that could help:

- Show if they have a higher risk than most people for certain cancers.
- Show if this increased risk could be passed to children or affect other family members.
- Change medical care and lifestyle choices for you and your family members, including recommendations for health screenings (tests to look for cancer).

Testing is usually done with a small sample of blood, but it can sometimes be done with saliva, cells from inside the cheek, or skin cells. It usually takes several weeks to get the results.

Biomarker testing

Biomarker testing is different from genetic testing. This testing is done using a sample of cancer cells—either a small piece of a tumor or a blood sample. Biomarker testing can help diagnose cancer, plan cancer treatment, or find out how well treatment is working. Not everyone with cancer needs to get genetic or biomarker testing. Ask your doctor if this type of testing could benefit you and your care.

Making decisions about genetic testing

To decide if genetic testing is recommended, your doctor will have a conversation with you to understand your risk and your family's history of cancer. They may ask which blood relatives (related by birth) were diagnosed with cancer, age at diagnosis, and what type of cancer they had. Some people feel uncomfortable discussing their family members' health with others, but keep in mind that your healthcare team wants to help and honor you and your family.

Your doctor may recommend that you also see a genetic counselor. This healthcare professional has specialized training in genetics and counseling. Genetic counselors describe the genetic testing in detail, including the pros and cons of testing. They explain how learning the information from having genetic testing could affect you, before you make this personal decision. If testing is done, they can explain what the results mean for you and for your family.

Remember, genetic testing is a personal choice; you do not have to have a genetic test to receive treatment for cancer.



Fertility

Many cancer treatments can affect fertility. Most likely, your doctor will talk with you about whether or not cancer treatment may increase the risk of, or cause, infertility. However, not all doctors bring up this topic. Sometimes you, a family member, or parents of a child being treated for cancer may need to initiate this conversation.

For some, infertility can be one of the most difficult and upsetting long-term effects of cancer treatment. Although it might feel overwhelming to think about your fertility right now, most people benefit from having talked with their doctor (or their child's doctor, when a child is being treated for cancer) about how treatment may affect their fertility and learning about options to preserve their fertility.

Talk with your doctor about the best option(s) for you based on your age, the type of cancer you have, and the specific treatment(s) you will be receiving. The success rate, financial cost, and availability of these procedures varies.

Pregnancy and breastfeeding

Many cancer treatments are harmful to a developing fetus. Ask your healthcare team if it is safe for you to have sex, become pregnant or make your partner pregnant. Some forms of birth control may not be recommended depending on your cancer diagnosis and type of treatment you are receiving. Your healthcare team can help you choose birth control that works for you and your partner. Be sure to tell your doctor if you are breastfeeding.

Common Types of Cancer Treatment

There are many types of cancer treatment. The types of treatment that you receive will depend on the type of cancer you have and how advanced it is. Some people with cancer will have only one treatment. But most people have a combination of treatments, such as surgery with chemotherapy and/or radiation therapy. When you need treatment for cancer, you have a lot to learn and think about. It is normal to feel overwhelmed and confused. But, talking with your doctor and learning about the types of treatment you may have can help you feel more in control.

Cancer surgery

Many people with cancer are treated with surgery. Surgery works best for tumors that are contained in one area. It is a local treatment, meaning that it treats only the part of your body with the cancer. It is not used for leukemia (a type of blood cancer). Sometimes surgery will be the only treatment you need. But most often, you will also have other cancer treatments.

Chemotherapy

What is chemotherapy?

Chemotherapy is the use of drugs to destroy cancer cells, usually by stopping the cancer cells' ability to grow and spread. Systemic chemotherapy gets into the bloodstream to reach cancer cells throughout the body. Chemotherapy is often used after surgery and/or radiation therapy to destroy any remaining cancer cells and lower the risk of recurrence. It may also be used to shrink a tumor before surgery or to treat metastatic or recurrent cancer. If it is not possible to get rid of the cancer, chemotherapy may be used to slow cancer growth or reduce symptoms, which is called palliative chemotherapy. Intravenous chemo, where drugs are injected directly into a vein (also known as IV chemo), and oral chemo (chemo drugs are swallowed) are common ways to administer chemotherapy.

Oral chemotherapy

You can take some drugs by mouth. They can be in a pill, capsule, or liquid. This means that you may be able to pick up your medication at the pharmacy and take it at home. Oral treatment for cancer is now more common, since many drugs used for targeted therapy work this way. Some of these drugs are given daily, and others are given less often. Oral chemo may have similar side effects to IV chemo, but often is more tolerable.

What should I expect during chemotherapy?

Before treatment, you will meet with a medical oncologist who will recommend a specific treatment schedule and explain the risks and benefits. If you choose to receive chemotherapy, you will be asked to give written permission. You will also have tests to help plan treatment. The doctor may also recommend addressing dental health, heart health, and fertility concerns before treatment.

You may receive chemotherapy at the doctor's office, an outpatient clinic, the hospital, or at home. Chemotherapy is often given for a specific time, such as for several weeks, several months, or longer. Or, you might receive chemotherapy for as long as it works. Doctors usually give these drugs with breaks between treatments, so you have time to rest and recover before the next treatment. This lets your healthy cells heal. Each dose and recovery time is called a "treatment cycle." Several treatment cycles make up a course of chemotherapy. A course usually lasts 3 months or more. Many people receiving IV chemotherapy have a port implanted under the skin, which is a small device that eliminates the need to find a vein at each treatment session.

Many cancer facilities offer chemo classes before chemotherapy begins to explain how it works in the body, and what side effects may occur during and after treatment, so you have an idea of what to expect.

Radiation therapy

What is radiation therapy?

Radiation therapy is the use of high-energy x-rays or other particles to kill cancer cells. The goal of radiation therapy is to destroy the cancer cells and slow tumor growth without harming nearby healthy tissue. It may be used along with other cancer treatments or as the main treatment. Sometimes radiation therapy is used to relieve symptoms, called palliative radiation therapy. More than half of all people with cancer receive some type of radiation therapy.

What should I expect during radiation therapy?

Before treatment begins, you will meet with the radiation oncologist to review your medical history and discuss the potential risks and benefits. If you choose to receive radiation therapy, you may undergo tests to plan the treatment and evaluate the results. Before radiation therapy begins, it must be planned carefully. This planning stage is often called a "simulation." During this visit, the medical team will figure out the best position for you to be in during treatment. Sometimes, permanent marks, or tattoo dots, will be made on the skin to help with daily setup for radiation therapy.



After the simulation, the best position for the radiation beams and appropriate shielding for healthy tissue will be decided. Treatment often begins a few days after the simulation. Your radiation oncologist will evaluate your progress regularly and may adjust your treatment plan as needed.

Immunotherapy

What is immunotherapy?

Immunotherapy is a treatment designed to boost the body's natural defenses to fight cancer. It uses materials made by the body or in a laboratory to boost, target, or restore a person's immune system. The immune system is a network of cells, tissues, and organs that work together to protect the body from infection.

Certain types of immunotherapy attack cancer or slow its spread to other parts of the body. Others make it easier for the immune system to destroy cancer cells. Your doctor may recommend immunotherapy after or at the same time as another treatment, such as chemotherapy. Or immunotherapy may be used by itself.

Hormone therapy

Hormone therapy is a treatment that slows or stops the growth of cancers that use the body's natural hormones to grow. This usually involves medications that block or decrease the body's production of certain hormones.

Bone marrow/stem cell transplant

A bone marrow transplant, also called a stem cell transplant, is a treatment for some types of cancer. For example, you might have one if you have leukemia, multiple myeloma, or some types of lymphoma. Doctors also treat some blood diseases with stem cell transplants. In the past, a stem cell transplant was more commonly called a bone marrow transplant because the stem cells were collected from the bone marrow.

Today, stem cells are usually collected from the blood, instead of the bone marrow. For this reason, they are now often called stem cell transplants. Your healthcare team will provide you with detailed information about this treatment if you are a candidate.

Personalized medicine (also known as precision medicine)

Personalized medicine helps doctors learn about a person's genetic makeup and how their tumor grows. With this information, doctors hope to find prevention, screening, and treatment strategies that may be more effective. They also want to find treatments that cause fewer side effects than the standard options.

By performing tests on the cancer cells and on normal cells, doctors may be able to customize treatment to each patient's needs.

Targeted therapy

Targeted cancer therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules ("molecular targets") that are involved in the growth, progression, and spread of cancer.

Targeted cancer therapies are sometimes called "molecularly targeted drugs," "molecularly targeted therapies," "precision medicines," or similar names. Cancer vaccines and gene therapy are sometimes considered targeted therapies because they interfere with the growth of specific cancer cells. These are more common in certain cancers.

Clinical trials (research studies)

A cancer clinical trial is a research study that helps doctors find better ways to prevent, treat, or cure cancer. There are many types of trials, and each one is different. Depending on the trial and its purpose, a patient may receive a completely new medicine (such as a chemotherapy drug), a new or different radiation therapy or surgery, or some combination of established treatments.

People volunteer to be in clinical trials. A volunteer can join if they meet the study requirements which can include: age, sex, type and stage of cancer, previous treatment history, and other medical conditions. There are clinical trials for all stages of cancer. Some trials are for people whose regular cancer treatments did not work. Others are for people who have tried some or all of the available treatments.

Some benefits of being in a clinical trial. You may:

- have access to the newest treatment options being researched for your cancer and receive potentially life-saving treatment.
- receive a new treatment doctors have studied and that may be better than the current standard treatment for you.
- help doctors find new and better treatment options to improve cancer care for future patients.

Some risks of being in a clinical trial:

- There is a chance the new treatment being researched may not be better or as effective as the standard treatment for you.
- The new treatment may have some unexpected and/or serious side effects during treatment or later.
- You may have to pay some out-of-pocket costs that are not covered by your insurance company or by the sponsor of the study.

There are different types of costs involved in clinical trials. Some trials require you to have health insurance, which may cover many of these costs. Some costs may be covered by the study sponsor, or you will be responsible for them. Some study sponsors and advocacy organizations offer financial assistance if you are uninsured or unable to pay the out-of-pocket costs.

Before joining a clinical trial, full details about the trial will be explained to you and given to you in writing. The U.S. government has strict rules to protect the rights, safety and confidentiality of people who volunteer to take part in clinical trials. All clinical trial doctors and staff must follow these rules. You can leave the clinical trial at any time and for any reason. Your doctor will discuss other treatment options for you at that time.

As you discuss cancer treatment options with your healthcare team, ask if a clinical trial is an option for you.

Learn More About Clinical Trials

- clinicaltrials.gov
- cancer.gov/research/participate/clinical-trials
- cisr.org

Making Decisions About Cancer Treatment

After a cancer diagnosis, people with cancer and their families have to make a number of decisions about treatment. These decisions are complicated by feelings of anxiety, unfamiliar words, statistics, and a sense of urgency. But unless the situation is extremely urgent, take time to research your options, ask questions, and talk with family or a trusted friend.

Decisions about cancer treatment are personal, and you need to feel comfortable with your choices. But many people do not know where to start. Here are some simple but important steps you can take as you start the decision making process.

Know your options

Talk with your doctor about the treatment options for your type and stage of cancer. (See **Common Types of Cancer Treatment** on page 14.)

Understand the goals of treatment

Your doctor may use some treatments to slow, stop, or eliminate the cancer. He or she may also use palliative care, also called supportive care, to manage symptoms and side effects. Make sure your doctor explains the goals of your treatment plan and how it will affect you. And make sure it aligns with your personal goals for treatment.

Ask about the side effects of each treatment option

Sometimes cancer can cause long-term side effects, or late effects, that might develop months or even years after treatment. Talk with your healthcare team about the possible long-term effects of each treatment option and how they are managed. In addition, discuss possible sexual or reproductive concerns with your healthcare team, including the risk of being unable to have children and your options to preserve fertility before treatment begins.

Consider the risks and benefits of each treatment option

Weigh the positives and negatives of each treatment option, including the:

- Chance of a cure.
- Potential short- and long-term side effects.
- Likelihood that the cancer will come back after treatment.
- Chances of living longer with or without treatment.
- Effect on your quality of life and independence.
- Preferences of you and your family.



Get a second opinion

Many people seek a second or even third opinion from another oncologist, and many doctors encourage it. Different oncologists may have different experiences with various treatments. So seeking multiple opinions can help you make a decision or confirm your current treatment plan. Find out if waiting to start treatment could be harmful or if you can begin treatment while getting another opinion.

Find help managing the cost of cancer care

The cost of cancer care is often high, and you may have expenses that you were not expecting. Your healthcare team can help you identify costs related to your treatment options or suggest ways to manage medical and related costs. They can also refer you to support services that address the financial concerns of people living with cancer.

Discuss your decision with people you trust

Some people find it helpful to talk through their thoughts and concerns with people they trust. This may include:

- Family members.
- Friends.
- A member of the clergy.
- A spiritual advisor.
- An oncology social worker.
- Another person with cancer.

Understand the role of statistics

Your doctor may mention statistics when describing treatment options. These may include relative survival rates, disease-free survival rates, and progression-free survival rates. These numbers may be a good way to learn how the treatment options differ. But they cannot predict how well the treatment will work for you. Your healthcare team can explain how these statistics relate to your treatment.



Questions to ask your healthcare team about cancer treatments

1. What are the goals of treatment?
2. What other treatment options do I have?
3. What are the expected short-term and long-term benefits of this treatment?
4. How will we know if the treatment is working?
5. When does the treatment need to start? How long will the treatment last?
6. If drugs are part of my treatment, which drugs will be used and what will they do?
7. Where, how, and how often will the treatment be given?
8. Can I pause or take a break from treatment?
9. How do you anticipate I will feel during treatment?
10. How may I need to modify my work schedule or lifestyle?
11. Do you expect any changes in my appearance as a result of treatment?
12. What side effects or symptoms do I report immediately, and to whom?
13. Are there any long-term risks or late effects of treatment?
14. How much will the treatment cost? Is it covered by my insurance?
15. Who do I talk to about insurance and/or obtaining financial assistance?
16. How might my treatment impact my family or friends? Are there any resources my caregivers should be aware of?

Scan for print version



Following Your Cancer Treatment Plan

Once you decide on your cancer treatment(s), your healthcare team will create a cancer treatment plan for you. This individualized roadmap is based on your cancer, your current health, your goals for treatment, and other factors. Review it with your team to hear details of the plan, treatment schedule, and what to expect along the way. Be sure to ask questions about anything you do not understand.

Your healthcare team has your best interests in mind when they give you medical advice and prescribe medications and other cancer treatments. It is important to stick with your care plan. Keep the conversation going when you have questions or concerns, especially if you are experiencing side effects. Often, these can be managed and relieved with a quick phone call between office visits, and your treatment can continue as planned.

These guidelines can help reduce your chance of infection or complications, and keep you and your caregivers safe. Your doctor or nurse may give you more detailed instructions based on the type or intensity of treatment you are receiving.

If you are receiving chemotherapy:

Trace amounts of chemotherapy may be present in body fluids for about 48 hours after receiving treatment. During this time period following chemotherapy it is recommended that you:

- Ask your nurse or doctor if you can have sexual intercourse and if you need to use a condom.
- Shut the lid before flushing your toilet.

- Have your caregivers wear gloves if they might experience contact with your body fluids during this time.
- Wash any laundry soiled with body fluids in hot water and separate from other items.

If you are receiving oral (taken by mouth) chemotherapy at home, talk to your healthcare team about how to safely store, handle, and dispose of chemo medicines and how to keep those around you safe.

If you are undergoing radiation therapy:

- Avoid sun exposure to the affected body parts.
- Avoid using harsh laundry detergents or products with fragrance as your skin will be more sensitive during treatment and for about 2 weeks after treatment.
- If you develop a rash, ask your doctor or nurse for recommendations regarding skin products or creams to help.

- If your treatment includes internal radiation treatment, such as implanted radiation seeds (brachytherapy) or taking a radioactive pill, your healthcare team will give you specific instructions and precautions for you and your caregivers to follow at home. This includes information about close physical contact with pregnant women, infants, children, and pets.

General precautions

- Avoid contact with ill persons and crowded places.
- Wash your hands frequently.
- Keep household surfaces clean.
- Ask your doctor which vaccines you should receive.
- Eat fresh food, prepared in a reputable establishment or at home. Wash or cook vegetables and fruits before consuming.
- Avoid undercooked or raw meat and eggs, as well as raw or unpasteurized products.

When to call your doctor right away

It is important to ask your healthcare team which signs and symptoms to expect, and which ones need medical attention right away. If you have any of the symptoms listed on page 40 or anything listed on the printed information given to you by your healthcare team, call your doctor right away.



Medication Tips

- Be sure to fill all the prescriptions you receive. See the Resources section of *My Companion Guidebook* if you need help paying for prescribed medications.
- Make sure you understand what medications you are taking, why, when, and how they are to be taken.
- Use the forms in *My Companion Guidebook* to list the medications, herbs and supplements you take and to make a medication schedule.
- Take medications at the right time of day and in the correct dose for the full duration prescribed—even if you feel better.
- Reach out to your healthcare team if you are experiencing symptoms that could be side effects of a medication.
- Follow the instructions of your doctor, nurse or pharmacist if you miss a dose or are late on a dose of any anti-cancer medications. This will reduce your chance of negative outcomes such as a serious side effect or progression of your cancer.
- Create a reminder system—use a calendar, an app, phone or other alarm.
- Include taking your medications as part of your daily routine. Ask your caregivers, family, and friends to remind you to take them on time.
- If you fly, be sure to pack your medications in your carry-on bag, never your checked luggage.

Supportive Cancer Care

Palliative care

What is palliative care?

Cancer often causes symptoms, and any treatment for cancer may cause side effects. An important part of your cancer care, regardless of diagnosis, is preventing or relieving these symptoms and side effects. Doing this helps keep you as comfortable as possible while maintaining the best possible quality of life from diagnosis through treatment and beyond. This is called palliative care. In addition to treating physical issues, such as pain, nausea, and fatigue, palliative care focuses on supporting your emotional, spiritual, and practical needs. It also supports the needs of your family and caregivers.

You can receive palliative care at any age and at any stage of illness. Receiving palliative care does not mean that you will no longer receive treatment for the disease. People often receive treatment to slow, stop, or eliminate cancer in addition to treatment to ease discomfort. In fact, research shows that people who receive both types of treatment often have less severe symptoms, a better quality of life, and report they are more satisfied with treatment. Ask your healthcare team about the ways palliative care might be helpful to you and your family. (See **Palliative care** on page 79.)



Complementary and integrative medicine

Some people with cancer may consider using complementary therapy in addition to standard cancer treatment. This approach is called integrative medicine when it has been discussed with and approved by your healthcare team. You may sometimes hear integrative medicine called complementary and alternative medicine (CAM). However, there are no true “alternatives” to cancer treatment. Many people use complementary therapies to:

- Reduce the side effects of cancer treatment.
- Improve their physical and emotional well-being.
- Improve their recovery from cancer.

Talk with your healthcare team before adding any therapies to your standard treatment. They can help you safely combine the therapies that are right for you. Complementary and integrative therapies include but are not limited to: acupuncture, massage, tai chi, music therapy, nutrition, exercise, and mind-body techniques such as meditation, yoga, imagery, relaxation and breathing techniques. (See **Supportive care** on page 34.)

Using natural remedies for cancer

Complementary and alternative medicine (CAM) therapies include a wide variety of botanicals and nutritional products, such as dietary supplements, herbal supplements, and vitamins. Some people with cancer may wonder if these methods can help or cure them. Others may choose to use them because they are part of their culture. Right now, there isn't enough evidence to show that they can cure cancer by themselves. But, some of these methods may be able to work together with the standard cancer treatment recommended by your oncologist. Some herbal or natural remedies may also help prevent or manage side effects of cancer or its treatment.

Natural or herbal remedies might seem safe, but they are not all safe. Some can be harmful and have serious side effects. They can change the way your medicines work, how your body responds to medicines, and even prevent your treatment (such as chemotherapy and radiation therapy) from working the way it should.

If this approach is important to you, don't be afraid to discuss it with your doctor before you start. Be prepared with your questions. You can also bring a product and related information, or share trusted websites with your doctor. They can talk about the risks and benefits of various methods so you can make an informed decision that respects your beliefs and values.

Learning to Relax

Many people with cancer have found that doing relaxation or imagery exercises has helped them cope with pain and stress. Take the time to learn helpful relaxation skills, such as the ones below, and practice them when you can. You can also take a class, find videos on YouTube, buy a relaxation DVD or CD, or find other exercises online.

Getting started

For each exercise, find a quiet place where you can rest undisturbed. Let others know you need time for yourself. Make the setting peaceful for you. For example, dim the lights and find a comfortable chair or couch. You may find that your mind wanders, which is normal. When you notice yourself thinking of something else, gently direct your attention back to your body. Be sure to maintain your deep breathing. Some people like to listen to slow, familiar music while they practice these exercises.

Breathing and muscle tensing

- Get into a comfortable position where you can relax your muscles. Close your eyes and clear your mind of distractions. You can sit up or lie down. If you're lying down, you may want to put a small pillow under your neck and knees.
- Breathe deeply, at a slow and relaxing pace. Concentrate on breathing deeply and slowly, raising your belly with each breath, rather than just your chest.
- Next, go through each of your major muscle groups, tensing (squeezing) them for a few seconds and then letting go. Start at the top of your head and work your way down. Tense and relax your face and jaws, then shoulders and arms.
- Continue tensing and relaxing each muscle group as you go down (chest, lower back, buttocks, legs), ending with your feet. Focus completely on releasing all the tension from your muscles and notice the differences you feel when they are relaxed.
- When you are done, focus on the pleasant feeling of relaxation for as long as you like.

Slow rhythmic breathing

- Stare at an object or shut your eyes and think of a peaceful scene. Take a slow, deep breath.
- As you breathe in, tense your muscles. As you breathe out, relax your muscles and feel the tension leaving.
- Remain relaxed and begin breathing slowly and comfortably, taking about 9 to 12 breaths a minute. To maintain a slow, even rhythm, you can silently say to yourself, "In, one, two. Out, one, two."
- If you ever feel out of breath, take a deep breath, and continue the slow breathing.
- Each time you breathe out, feel yourself relaxing and going limp. Continue the slow, rhythmic breathing for up to 10 minutes.

[3]

Coping with Cancer

Your Emotions

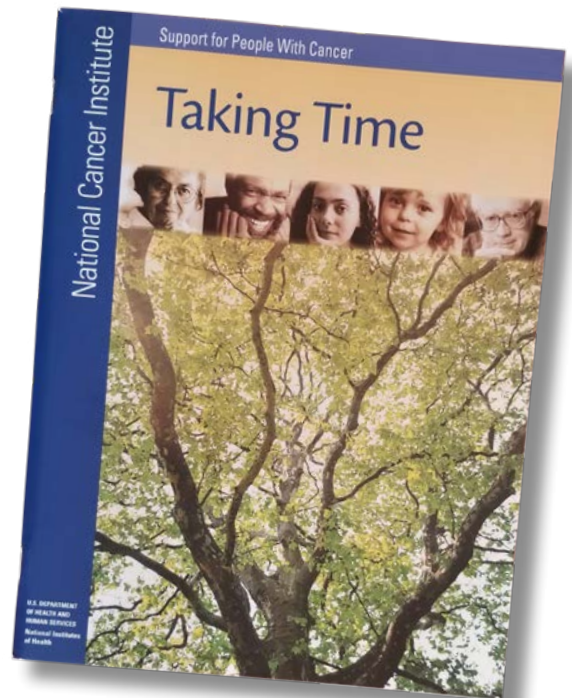
A cancer diagnosis usually brings with it a flood of emotions—for you and everyone around you.

In your **Bag It** bag you'll find the booklet entitled *Taking Time* from the National Cancer Institute. It can help you understand and cope with concerns you may have about:

- Your feelings about having cancer.
- Changes in your roles and relationships, with yourself, spouse/partner, family members, and close friends.
- Talking to others, including young or adult children.
- Where and how to build your team for support.

Use what is helpful in the booklet today or look at it later when you are ready. Share it with those around you as you see fit.

Additional information is available on our website: BagItCancer.org/resources



Anxiety and distress

Patients living with cancer feel many different emotions, including anxiety and distress. Anxiety is fear, dread, and uneasiness caused by stress. Anxiety may increase pain, affect sleep, and cause nausea and vomiting.

Distress is an unpleasant experience of mental, physical, social, or spiritual nature. It can affect the way you think, feel or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment. Most people with cancer feel distress at some point, which is perfectly normal. Distress can range from mild to severe. Caused by many factors, the concerns and symptoms of distress vary from person to person.

NCCN Guidelines Version 1.2024 Distress Management

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress

No distress

PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

Emotional Concerns

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

Social Concerns

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children
- Prejudice or discrimination

Practical Concerns

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care
- Having enough food
- Access to medicine
- Treatment decisions

Spiritual or Religious Concerns

- Sense of meaning or purpose
- Changes in faith or beliefs
- Death, dying, or afterlife
- Conflict between beliefs and cancer treatments
- Relationship with the sacred
- Ritual or dietary needs

Other Concerns:

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Part of your cancer care includes being screened for distress by your healthcare team. You may be asked how you are feeling and any concerns you might have in areas of your life, such as relationships and your job. Or, you may be asked to complete a survey or a checklist like the example shown above. It is important to be honest in your responses. Let your healthcare team know how you are doing and what your concerns are so they can offer other services and support you may need.

Depression

Many people with cancer feel sad. They feel a sense of loss of their health, and the life they had before they learned they had the disease. This is a common response to any serious illness. It may take time to work through and accept all the changes that are taking place.

When you're sad, you may have very little energy, feel tired, or not want to eat. For some, these feelings go away or lessen over time. But for others, these emotions can become stronger. The painful feelings don't get any better, and they get in the way of daily life. This may mean you have depression. Depression can be treated. Below are common signs of depression. If you have any of the following signs for more than 2 weeks, talk to your doctor about treatment.

Emotional signs

- | | |
|--|--|
| <ul style="list-style-type: none">• Feelings of sadness that don't go away• Feeling emotionally numb• Having a sense of guilt or feeling unworthy• Feeling helpless or hopeless, as if life has no meaning• Feeling short-tempered, moody, nervous or shaky• Having a hard time concentrating, feeling scatterbrained | <ul style="list-style-type: none">• Crying for long periods of time or many times each day• Focusing on worries and problems• No interest in the hobbies and activities you used to enjoy• Finding it hard to enjoy everyday things, such as food or being with family and friends• Thinking about hurting or killing yourself |
|--|--|

Body changes

- | | |
|--|--|
| <ul style="list-style-type: none">• Unintended weight gain or loss not due to illness or treatment• Sleep problems, such as not being able to sleep, having nightmares, or sleeping too much• Racing heart, dry mouth, increased perspiration, upset stomach, diarrhea | <ul style="list-style-type: none">• Pain or burning during urination; frequent urination• Changes in energy level• Fatigue that doesn't go away• Headaches, other aches and pains |
|--|--|

Treatment of depression may include talk therapy, medicines, or both. Getting the help you need is important for your life and your health.

Feelings of hopelessness may lead to thoughts about suicide. If you or someone you know is thinking about suicide, get help as soon as possible. The 988 Suicide & Crisis Lifeline is available anytime. For English, call 1-800-273-TALK (8255) or call, text or chat 988. For Spanish, press 2.

The Importance of Communication

Good communication is important in relationships between people with cancer and those who care about them. A lack of communication often leads to isolation, frustration, and misunderstandings.

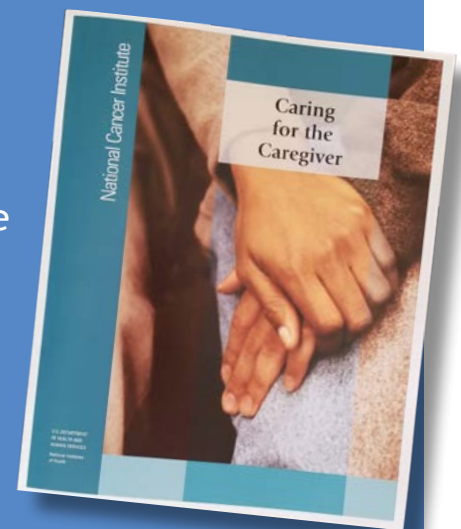
As any person with cancer knows, a cancer diagnosis also affects family members and friends. Sometimes, the complex feelings and lifestyle changes caused by cancer and its treatment become as overwhelming for others in your life as they are for you. Understanding the potential changes in the way you relate to specific family members and friends may help you take steps to foster healthy, mutually supportive relationships during this challenging time.

Spouses and partners

Cancer has the greatest effect on marriages and other long-term partnerships. After a cancer diagnosis, both individuals may experience sadness, anxiety, anger, or even hopelessness. The effects of cancer vary from couple to couple. For some couples, facing the challenges of cancer together strengthens their relationship. For others, the stress of cancer may create new problems or worsen existing problems.

For Your Caregiver(s)

In your Bag It bag you'll find the booklet entitled *Caring for the Caregiver* from the National Cancer Institute. Give this booklet to family members and those at your side as well as long-distance loved ones. It gives helpful tips on how caregivers can support you while making sure they also take good care of themselves. Long-distance caregivers and loved ones can download it or read it online at BagItCancer.org/resources.



Friends and adult family members

The effects of cancer on your relationships with friends and family members vary widely, based on the closeness of each relationship. Different families have different communication and coping styles. Consider how your family reacts in a crisis and how family members have dealt with other difficult situations. This will help you plan your strategy for communicating news and asking for support.

Talking with your children about cancer

If a family member has cancer, children often sense that something is wrong. Or they may overhear conversations. They tend to worry more if they feel that important news is being kept from them. As a parent or guardian, you may want to protect your children from distressing news, such as cancer. But avoiding the topic may confuse children and make them fear a worst-case situation. It is also important to remember that children share information with each other.

The whole family should work together to decide what and how much to tell the children about a family member's cancer diagnosis. This can help avoid confusing or misleading information being passed among the children.

Tips for talking with your children

A child's parents or primary guardian should take the lead in discussing a family member's cancer diagnosis. As you talk with your children, listen to their concerns and answer their questions to the best of your ability. Here are some tips to help you talk with your children about cancer:

- Use the term "cancer." It gives your children specific information and reduces confusion and misunderstanding.
- Use age-appropriate language to discuss cancer. Younger children need a simpler explanation. For older children, a more detailed explanation helps reduce feelings of helplessness and fear.

Find more information and tips about talking with children of different ages at BagitCancer.org/resources.

Talking about feelings and personal needs with honesty, sincerity, and openness greatly reduces the stress on relationships. If you are having a hard time talking with people, or if others don't seem to want to communicate with you, consider asking for help by joining a support group or talking with a counselor or social worker.

*“With communication comes understanding and clarity;
with understanding, fear diminishes;
in the absence of fear, hope emerges;
and in the presence of hope, anything is possible.”*



*- Ellen Stovall
3-time cancer survivor
and former CEO of NCCS*

Your Faith and Spirituality

Many people with cancer look more deeply for meaning in their lives. They want to understand their purpose in life or why they got cancer. Spirituality means the way you look at the world and how you make sense of your place in it. Spirituality can include faith or religion, beliefs, values, and "reasons for being."

What being spiritual may mean to you

Being spiritual can mean different things to everyone. It's a very personal issue. Everyone has their own beliefs or practices such as:

- Finding it through religion or faith.
- Practicing certain rituals.
- Meditating or yoga.
- Volunteering or doing things for others.
- Teaching.
- Reading or writing.
- Being in nature or with animals.

How cancer may affect your spirituality or faith

Having cancer may cause you to think about what you believe, whether you're connected to a traditional religion or not. It's normal to view the experience both

negatively and positively at the same time. Some people find that cancer brings more meaning to their faith. Others feel that their faith has let them down and they struggle to understand why they have cancer.

Some people look for a sense of peace or connection with loved ones. They find that having cancer causes them to enhance their bonds with the people closest to them. Others try to forgive themselves for past actions they took or didn't take. Or they look to forgive others and make it a time for healing relationships. While you may realize what's important to you, it's also normal to feel distressed. Some people have feelings of uncertainty about their purpose in life. Others have a lack of hope or worries about their loved ones.

Your values may change

Many people also find that cancer changes their values. They make changes to reflect what matters most to them now. The things you own and your daily duties may seem less important. You may decide to spend more time with loved ones or do something to help others. Or you may take more time to do things in the outdoors or learn about something new. For some, faith can be an important part of both coping with and recovering from cancer.

Finding comfort and meaning during cancer

If you want to find faith-based or spiritual support, many hospitals have chaplains who are trained to give support to people of different faiths, as well as those who aren't religious at all. You could also ask your healthcare team about local experts or organizations that help cancer patients and survivors. Some ideas that have helped others find comfort and meaning are:

- Praying or meditating.
- Talking with members of your spiritual community.
- Reading uplifting stories about the human spirit.
- Talking with others with similar experiences.
- Taking time alone to reflect on life and relationships.
- Writing in a journal.
- Finding a special place where you find beauty or a sense of calm.
- Taking part in community or social gatherings for support and to support others.

Side Effects of Treatment

Cancer treatments can span weeks, months, or perhaps the rest of your life. The treatments may affect how you physically look and feel. Side effects can be different for everyone, even if they're getting the same treatment. Your healthcare

team will talk to you about potential side effects and how to deal with them. Don't be afraid to ask questions. Do not delay reporting new symptoms—keeping your healthcare team informed enables them to give you the best care and manage side effects, so you feel better.

Some side effects go away once your treatment ends. Long-term side effects can last for months or years after treatment is completed. Late effects develop months or even years after treatment is completed. (See **Physical Changes and Side Effects** on page 70.)

Supportive care

Palliative care and some complementary therapies offer ways to prevent, manage, and/or relieve cancer-related discomfort. They can improve your quality of life physically and emotionally.

Many people find relief from complementary therapies. While they do not work for everyone, they may help you manage stress, nausea, pain, or other symptoms and side effects. Caregivers and families can also benefit from some therapies for stress and anxiety.

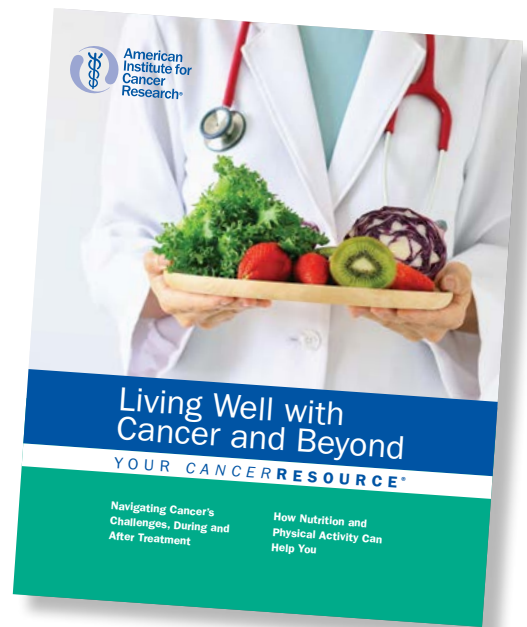
Ask your healthcare team what would be appropriate for you at that time, as some are not recommended at all times. Be sure to talk to your doctor before you try anything new. Many cancer centers, hospitals, and oncology care providers offer these services, often at little or no charge. Refer to the Resources section in *My Companion Guidebook* for more information on how to find service providers.

Treatment/therapy:	May relieve:
Massage therapy	Fatigue, weakness, anxiety/stress, insomnia, pain and peripheral neuropathy, lymphedema
Yoga: Stretches and poses with a focus on breathing	Fatigue, weakness, anxiety/stress, insomnia, pain and peripheral neuropathy, nausea
Acupuncture	Nausea, fatigue and weakness, anxiety/stress, insomnia, lymphedema, pain and peripheral neuropathy
Tai Chi: Slow, gentle movements with controlled breathing and concentration	Fatigue, weakness, anxiety/stress, insomnia, pain
Meditation: Focused breathing or repetition of words or phrases to quiet the mind	Fatigue, weakness, anxiety/stress, insomnia, pain, nausea

Common side effects

The *CancerResource® Living Well with Cancer and Beyond* booklet in your **Bag It** bag gives guidance on diet, nutrition, and physical activity during and after cancer treatment.

- Managing common side effects
 - › Nausea, vomiting, bowel changes
 - › Changes in taste and smell, food aversion
 - › Sore or dry mouth, tongue or throat, difficulty swallowing
 - › Changes in appetite and weight
- The rewards of staying active
- Tips for a healthy lifestyle
- Other nutrition topics related to cancer



Cancer-related fatigue

What is cancer-related fatigue?

Cancer-related fatigue may feel like persistent physical, emotional, and mental exhaustion. It is different from feeling tired after not getting enough rest. Fatigue interferes with daily life, does not match your activity level, and does not go away if you rest. Most people receiving cancer treatment experience fatigue, and some people will continue to experience fatigue after treatment is over. If you experience fatigue, it is important to tell your doctor. Fatigue can cause a person with cancer to avoid or skip treatments. It may also negatively affect other areas of life, including mental and physical health, relationships, and work.

What causes cancer-related fatigue?

Most people receiving chemotherapy, radiation therapy, surgery, or other treatments experience fatigue. This fatigue may be caused by a low level of red blood cells, called anemia, or hormone levels that are too low or too high. Side effects related to nutrition, such as loss of appetite or dehydration, may result in fatigue, as can a lack of exercise. Anxiety and depression are the most common psychological reasons fatigue occurs. Pain, stress, lack of sleep, medications, and other medical conditions can also cause fatigue.



How is cancer-related fatigue treated?

The first step in managing fatigue is to treat any medical condition causing or worsening your fatigue, such as pain, depression or anxiety, lack of sleep, poor nutrition, anemia, cancer treatment, or other medical conditions. If the cause is not known, you may need to try several methods to reduce or manage fatigue. Staying physically active or increasing your activity level can help relieve fatigue. Once you are healthy enough for physical activity, try to include moderate aerobic activity, such as fast walking, cycling, or swimming, plus strength training. Talk with your doctor about the right exercise routine for you. Talking with a therapist or counselor may help you reframe your thoughts about fatigue and improve coping skills and/or sleep problems. In addition, some people find that yoga, acupuncture, and mindfulness practices may help as well. (See **Supportive care** on page 34.)

Pain

Pain can be a common side effect of cancer and its treatment. It can also make other symptoms or side effects of cancer seem worse. But, nearly all cancer pain can be managed, with or without the use of medication. Pain specialists, or pain medicine doctors, are experts at finding the cause of pain and treating it. They may prescribe medication, recommend a rehabilitation program, and/or perform pain-relieving procedures. An oncologist or palliative medicine physician may be able to control your pain without referring you to a pain specialist.

Talk to your doctor about your goals for management of your pain.

What causes pain?

People with cancer may experience pain caused by the cancer itself or as a side effect of treatment. For example, a tumor may press on bones, nerves, the spinal cord, or organs, causing pain. Pain may also develop after surgery, radiation therapy, or chemotherapy. Pain usually gets better over time, but some people may experience pain for months or years as a result of permanent damage to the nerves. Some pain, such as arthritis, lower back pain, or migraines, may not be related to the cancer at all. However, it is still important to tell your healthcare team about this type of pain so it can be addressed as part of your overall treatment plan.

What are the various types of pain?

There are different types of cancer pain. Pain may last just a short time after a particular treatment or other event. Pain may only occur from time to time. Or, pain may be long-lasting and constant. Pain may also increase suddenly even though it is being treated. This is called breakthrough pain. It typically occurs between scheduled doses of pain medication, but it may not be linked to a specific movement or time of day.

What does the doctor or nurse need to know about my pain?

Tell your healthcare team about any type of pain you experience. The healthcare team's role in managing pain is to listen to your concerns and offer a solution. They may ask you to explain the intensity of the pain using a scale from 0 to 10 or use words, such as "burning," "stabbing," or "throbbing," to help describe the pain. You should write down when and where your pain occurs and note whether anything makes the pain worse or better. Some people find that keeping a pain journal helps.

What are the treatment options for pain?

Doctors can manage pain by treating the source of the pain; changing how a person feels pain, usually with pain-relieving medications; or interfering with pain signals sent to the brain through spinal treatments or nerve blocks. If medication is needed, non-opioid painkillers, such as acetaminophen and ibuprofen, are used for mild to moderate pain. Doctors may also prescribe other medications, such as antidepressants or anti-seizure medicines, to help relieve some pain, particularly nerve pain.

Opioids, such as morphine, may be used along with other treatments when other methods have not worked. In addition, where it is legal, medical cannabis or cannabinoids could be an option, along with other methods for unrelieved pain.

Many people also find relief through complementary treatments, including physical and occupational therapy, acupuncture, and mindfulness practices, such

as meditation or breathing exercises. A pain management plan may include a combination of medication and complementary methods, which are therapies, techniques, and products used in addition to conventional treatments. (See **Supportive care** on page 34.)

Lymphedema

Lymphedema occurs when lymph fluid builds-up and causes swelling. It usually affects an arm or leg, but it can also affect other parts of the body, such as the head and neck. You may notice symptoms of lymphedema at the part of your body where you had surgery or received radiation therapy. Swelling usually develops slowly, over time. It may develop during treatment or it may start years after treatment. Call your healthcare team as soon as you notice symptoms. Early treatment may prevent or reduce the severity of problems caused by lymphedema.

At first, lymphedema in an arm or leg may cause symptoms such as:	Lymphedema in the head or neck may cause:
<ul style="list-style-type: none">• Swelling and a heavy or achy feeling in your arms or legs that may spread to your fingers and toes.• A dent when you press on the swollen area.• Swelling that is soft to the touch and is usually not painful at first.	<ul style="list-style-type: none">• Swelling and a tight uncomfortable feeling on your face, neck, or under your chin.• Difficulty moving your head or neck.

Lymphedema that is not controlled may cause:
<ul style="list-style-type: none">• More swelling, weakness, and difficulty moving your arm or leg.• Itchy, red, warm skin, and sometimes a rash.• Wounds that don't heal, and an increased risk of skin infections that may cause pain, redness, and swelling.• Thickening or hardening of the skin.• Tight feeling in the skin; pressing on the swollen area does not leave a dent.• Hair loss.

Ways to manage lymphedema

Steps you may be advised to take to prevent lymphedema or to keep it from getting worse:

- **Protect your skin.** Use lotion to avoid dry skin. Use sunscreen. Wear plastic gloves with cotton lining when working in order to prevent scratches, cuts, or burns. Keep your feet clean and dry. Keep your nails clean and short to prevent ingrown nails and infection. Avoid tight shoes and tight jewelry.

- **Exercise.** Work to keep body fluids moving, especially in places where lymphedema has developed. Start with gentle exercises that help you to move and contract your muscles. Ask your doctor or nurse what exercises are best for you.
- **Manual lymph drainage.** See a trained specialist (a certified lymphedema therapist) to receive a type of therapeutic massage called manual lymph drainage. Therapeutic massage works best to lower lymphedema when given early, before symptoms progress.

Ways to treat lymphedema

Your doctor or nurse may advise you to take these and other steps to treat lymphedema:

- **Wear compression garments or bandages.** Wear special garments, such as sleeves, stockings, bras, compression shorts, gloves, bandages, and face or neck compression wear. Some garments are meant to be worn during the day, while others are to be worn at night.
- **Other practices.** Your healthcare team may advise you to use compression devices (special pumps that apply pressure periodically) or have laser therapy or other treatments.

Neutropenia and infection

Neutropenia is when a person has a low level of neutrophils. Neutrophils are a type of white blood cell. Neutrophils fight infection by destroying harmful bacteria and fungi (yeast) that invade the body. Half of the people with cancer who are receiving chemotherapy have some level of neutropenia. People who have neutropenia have a higher risk of getting serious infections. This is because they do not have enough neutrophils to kill organisms that cause infection. People with severe or long-lasting neutropenia are most likely to develop an infection. (See **Following Your Cancer Treatment Plan** on page 22 for tips on how to avoid infection.)

Signs and symptoms of neutropenia

Neutropenia itself may not cause any symptoms. Patients usually find out they have neutropenia from a blood test or when they get an infection. Some people will feel more tired when they have neutropenia. Your doctor will schedule regular blood tests to look for neutropenia and other blood-related side effects of chemotherapy. For patients with neutropenia, even a minor infection can quickly become serious.

Infection and when to call the doctor during cancer treatment

Cancer and cancer treatments may cause side effects that need medical attention. But it can be hard to know when to call the doctor. It is important to ask your healthcare team which signs and symptoms to expect, and which ones need medical attention right away.

Infection during cancer treatment can be life threatening. Your healthcare team will help you determine if the infection is serious and how best to manage your symptoms.

Immediately call your healthcare team if you have 1 or more of these symptoms:	Promptly call your healthcare team if you have 1 or more of these symptoms:
<ul style="list-style-type: none">• Fever – a temperature that is 100.4° F (38° C) or higher• Shaking chills or sweating• Chest pain, cough or shortness of breath• Confusion• Severe earache or headache with a stiff neck• Bloody urine	<ul style="list-style-type: none">• Cloudy urine• Pain or burning during urination; frequent urination• Sore throat, sores in the mouth, white coating in the mouth, or a toothache• Abdominal pain; diarrhea• Pain or sores near the anus• Any redness, swelling, discharge or pain (especially around a cut, wound, port or catheter)• Unusual vaginal discharge or itching

Fever danger: a fever can turn serious quickly. If you go to the ER, immediately tell them you are a patient on chemo and have a fever.

Tips to avoid infections during hospital stays:	
<ul style="list-style-type: none">• Wash your hands often with soap and water. Keep hand sanitizer bedside.• Use disinfectant wipes to wipe down surfaces in your room.• Kindly remind healthcare workers to wash their hands if you don't see them do so before they care for you.• Ask your visitors to wash their hands or use hand sanitizer when they enter your room.	<ul style="list-style-type: none">• Consider limiting the number of visitors you have. Decline visits from those who are ill.• Don't touch your wounds or surgical sites.• Notify a nurse if your bandages become wet or any body part becomes red or swollen.• If you are provided with a spirometer, use it regularly to keep your lungs healthy.

Neuropathy or peripheral neuropathy or nerve damage

Some cancer treatments cause peripheral neuropathy, a result of damage to the peripheral nerves. These nerves carry information from the brain to other parts of the body. Side effects depend on which peripheral nerves (sensory, motor, or autonomic) are affected.

If you start to notice any of the problems listed on the next page, talk with your doctor or nurse. Getting these problems diagnosed and treated early is the best way to control them, prevent further damage, and to reduce pain and other complications.

Damage to sensory nerves (nerves that help you feel pain, heat, cold and pressure) can cause:

- | | |
|---|--|
| <ul style="list-style-type: none">• Tingling, numbness, or a pins-and-needles feeling in your feet and hands that may spread to your legs and arms. | <ul style="list-style-type: none">• Inability to feel a hot or cold sensation, such as a hot stove.• Inability to feel pain, such as from a cut or sore on your foot. |
|---|--|

Damage to motor nerves (nerves that help your muscles to move) can cause:

- | | |
|--|--|
| <ul style="list-style-type: none">• Weak or achy muscles. You may lose your balance or trip easily. It may also be difficult to button shirts or open jars.• Muscles that twitch and cramp or muscle wasting (if you don't use your muscles regularly). | <ul style="list-style-type: none">• Swallowing or breathing difficulties (if your chest or throat muscles are affected). |
|--|--|

Damage to autonomic nerves (nerves that control functions such as blood pressure, digestion, heart rate, temperature, and urination) can cause:

- | | |
|--|--|
| <ul style="list-style-type: none">• Digestive changes such as constipation or diarrhea.• Dizzy or faint feeling, due to low blood pressure.• Sweating problems (either too much or too little sweating). | <ul style="list-style-type: none">• Sexual problems; men may be unable to get an erection and women may not reach orgasm.• Urination problems, such as leaking urine or difficulty emptying your bladder. |
|--|--|

Anemia

What is anemia?

Anemia is an abnormally low level of red blood cells that occurs when the body does not make enough blood, loses blood, or destroys red blood cells. It is common in people with cancer, especially those receiving chemotherapy. Red blood cells contain hemoglobin, an iron-containing protein that carries oxygen to all parts of the body. If red blood cell levels are too low, parts of the body do not get enough oxygen and cannot work properly.

What are the symptoms of anemia?

Most people with anemia feel tired or weak. Other symptoms may include rapid heartbeat, shortness of breath, chest pain, dizziness, pale skin, headaches, difficulty concentrating, insomnia (trouble falling asleep or staying asleep), and cold hands and feet. However, people with mild anemia may not experience any symptoms.

What are the treatment options for anemia?

Treatment for anemia depends on your symptoms and the cause of anemia. Some people who experience anemia symptoms need a transfusion of red blood cells. If the anemia is caused by a lack of nutrients, the doctor may prescribe vitamin B12, iron, or folic acid supplements.

Cancer-related cognitive impairment (also known as “chemobrain”)

Cognitive problems like memory loss, difficulty thinking and paying attention are commonly experienced by individuals during and after cancer treatment. Many people refer to these cognitive changes as “chemo brain.” But these changes can be caused by the cancer itself, and can also be due to cancer treatments other than chemotherapy, like radiation therapy, hormone therapy, and surgery.

Cognitive problems occur when a person has trouble processing information. Cancer survivors with chemobrain have cognitive problems that prevent them from thinking clearly. Symptoms may include trouble concentrating or focusing, mental fog or disorientation, and difficulties with judgment or reasoning. Memory loss and forgetting certain things, especially names, dates, and numbers, are also symptoms of chemobrain. The intensity of these symptoms often depends on several factors. This includes a person’s age, stress level, history of depression or anxiety, coping skills, and access to psychological support resources. These problems vary in severity and often make it hard to complete daily tasks.



The causes of chemobrain are not well understood. Research continues on the effect of cancer medications and other treatments on the brain. The general stress of having cancer and going through treatment may be a factor in the development of chemobrain. Hormonal changes and emotional distress may also play a role.

There is no specific laboratory or x-ray test that can be used to diagnose chemobrain. However, before assuming that new cognitive symptoms are a result of chemobrain, it is important to make sure that the symptom is not caused by a different condition related to cancer or its treatment. Examples of other causes of cognitive symptoms include anemia, electrolyte imbalances, sleep disturbances, fatigue, depression, previous brain surgery or cancer involving the brain, and other medications, particularly pain medicine. It is important to identify these causes of cognitive symptoms because many can be treated quickly and effectively.

There is no specific treatment for chemobrain, but several approaches are often effective in managing symptoms. These may include medications, occupational therapy to help with daily tasks and job-related skills, and cognitive training to help improve cognitive skills. There are also strategies to help cancer survivors better cope with attention, thinking, and memory difficulties, such as keeping a checklist of daily reminders, performing one task at a time, and using wordplay to help remember things. Try brain-strengthening mental activities, like solving crosswords or puzzles, painting, playing a musical instrument, or a new hobby.

And many cancer survivors have issues that continue for months after finishing treatment. Usually, these symptoms slowly improve. In most people, symptoms disappear within 4 years.

Get plenty of rest and make time for physical activity to increase mental alertness. Don't be afraid to ask your family and friends for help. Talk with your employer if you are having problems at work.

Sleep problems

Sleep problems such as being unable to fall asleep and/or stay asleep, also called insomnia, are common among people being treated for cancer. Studies show that as many as half of all patients have sleep-related problems. These problems may be caused by the side effects of treatment, medicine, long hospital stays, or stress. Sleeping well is important for your physical and mental health. A good night's sleep not only helps you to think clearly, it also lowers your blood pressure, helps your appetite, and strengthens your immune system. Sleep problems that go on for a long time may increase the risk of anxiety or depression. There are steps that you and your healthcare team can take to help you sleep well again.

- **Tell your doctor about problems that interfere with sleep.** Getting treatment to lower side effects such as pain or bladder or gastrointestinal problems may help you sleep better.

- **Cognitive behavioral therapy (CBT) and relaxation therapy may help.** Practicing these therapies can help you to relax. For example, a CBT therapist can help you learn to change negative thoughts and beliefs about sleep into positive ones. Strategies such as muscle relaxation, guided imagery, and self-hypnosis may also help you.
- **Set good bedtime habits.** Go to bed only when sleepy, in a quiet and dark room, and in a comfortable bed. If you do not fall asleep, get out of bed and return to bed when you are sleepy. Stop watching television or using other electrical devices a couple of hours before going to bed. Don't drink or eat a lot before bedtime. While it's important to keep active during the day with regular exercise, exercising a few hours before bedtime may make sleep more difficult.
- **Sleep medicine may be prescribed.** Your doctor may prescribe sleep medicine, for a short period if other strategies don't work. The sleep medicine prescribed will depend on your specific problem (such as trouble falling asleep or trouble staying asleep) as well as other medicines you are taking.

Hair loss (alopecia)

Hair loss is a common side effect of many cancer treatments. This is because the cancer treatments can harm the healthy cells that help hair grow. It is a common misconception that all cancer treatments cause hair loss. Whether or not your hair is affected by cancer treatment depends on the type of treatment and the dose. Before you begin treatment, ask your doctor if the recommended treatment plan can cause changes to your hair.



Cancer treatments can cause hair to fall out completely, change texture and appearance, or get thinner. It can affect hair all over your body, including your head, face, arms, legs, underarms, and pubic area. Most of the time, hair grows back after cancer treatment ends. For example, hair usually starts to grow back 1 to 3 months after chemotherapy ends. It often takes 6 to 12 months to grow back completely. It may grow back thinner, coarser, curly, or a different color. Hair usually goes back to normal over time. However, sometimes hair changes caused by cancer treatment are permanent. This includes hair loss.

A cooling cap is a device designed to reduce hair loss during chemotherapy—for use by patients with any kind of solid tumor. A tightly fitted cap in which cold liquid circulates to cool the scalp before, during, and after chemotherapy. Cooling the scalp causes blood vessels to constrict, which may limit the amount of chemotherapy drug that reaches hair follicles. The most common side effects of the scalp cooling system included headaches induced by the cold, neck and shoulder discomfort, and pain associated with wearing the cooling cap for extended periods. Results may vary so speak with your healthcare team to find out if a cooling cap is an option for you.

Skin and nail changes during cancer treatment

Cancer treatments may cause a range of skin and nail changes. Talk with your healthcare team to learn whether or not you will have these changes, based on the treatment you are receiving.

- **Radiation therapy** can cause the skin on the part of your body receiving radiation therapy to become dry and peel, itch (called pruritus), and turn red or darker. It may look sunburned or tan and be swollen or puffy.
- **Chemotherapy** may damage fast growing skin and nail cells. This can cause problems such as skin that is dry, itchy, red, and/or that peels. Some people may develop a rash or sun sensitivity, causing them to sunburn easily. Nail changes may include dark, yellow, or cracked nails and/or cuticles that are red and hurt. Chemotherapy in people who have received radiation therapy in the past can cause skin to become red, blister, peel, or hurt on the part of the body that received radiation therapy. This is called radiation recall.
- **Targeted therapy** may cause dry skin, a rash (which can be severe), and nail problems. Your doctor or nurse may give you specific skin instructions if you are receiving targeted therapy with certain medicines like EGFR inhibitors; be sure you and your caregivers understand them.

These skin problems are more serious and need urgent medical attention:

- Sudden or severe itching, a rash, or hives during chemotherapy. These may be signs of an allergic reaction.

- Your rash worsens and you develop painful, weeping sores. This is called a moist reaction and may happen in areas where the skin folds, such as around your ears, breast, or bottom, or in the area where you are receiving radiation treatment.

Your doctor or nurse will talk with you about possible skin and nail changes and advise you on ways to treat or prevent them.

Changes in your sex life

It's common for people to have problems with sex because of cancer and its treatment. When your treatment is over, you may feel like having sex again, but it may take some time. Sexual problems can last longer than other side effects of cancer treatment. It's important to seek help in learning how to adapt to these changes.

- **Tell your partner how you feel.** Talking to your loved one and sharing your feelings and concerns is very important. Even for a couple that has been together a long time, it can be hard to stay connected. Let your partner know if you want to have sex or would rather just hug, kiss, and cuddle. He or she may be afraid to have sex with you. Or your partner may be worried about hurting you or think that you're not feeling well. Talk to your partner about any concerns you have about your sex life. Be open about your feelings and stay positive to avoid blame.
- **Ask for help.** Even though you may feel awkward, let your doctor or nurse know if you're having problems with intimacy or sex. There may be treatments or other ways you and your loved one can give each other pleasure. If your doctor can't talk with you about sexual problems, ask for the name of a doctor who can. Some people also find it helpful to talk with other couples.

Use the customizable log in section 2 of My Companion Guidebook to keep track of side effects and symptoms you are experiencing. Note frequency, duration and intensity. Bring a copy to your next doctor visit.

Hot flashes and night sweats

Hot flashes and night sweats are common in patients receiving cancer treatment. Cancer treatments that can cause hot flashes and night sweats include:

- Surgery.
- Chemotherapy.
- Radiation therapy.
- Hormone therapy, such as antiestrogens.
- Other drug therapy.

Hot flashes are caused by hormonal changes in your body. Your face, chest, and other areas might suddenly get very hot and sweaty. You might feel your face getting red. Hot flashes usually last just a few minutes. You might wake up soaked in sweat.

Cope with hot flashes by:

- Dressing in layers. Wear a sweater or jacket that you can take off.
- Being active. Add walking, biking, swimming, or other types of exercise to your daily routine.
- Reducing stress. Besides getting regular exercise, try yoga, meditation, or relaxation exercises.

At night, sleep in cotton pajamas and sheets. Keep the room temperature cool and consider using a fan. Keep cool water at your bedside.

Some people continue to have hot flashes and night sweats after completing cancer treatment. If your hot flashes are severe, speak with your healthcare team about medications that may be able to reduce them.

Genital and urinary problems

These can include vaginal and vulvar dryness, itching, irritation, painful sex, urinary frequency or urgency, urinary leaks, and more frequent urinary tract infections.

- **Vaginal problems.** These can include dryness, painful sex, itching, irritation, and fluid (discharge) from your vagina.
- **Bladder problems.** You might leak urine, need to go more often than usual, or have trouble waiting until you can get to a bathroom. You might also get urinary tract infections.

There are several different ways to treat a dry or sensitive vulva and vagina. These treatments can also help with bladder problems such as urinary frequency and urgency. Some of these treatments include hormones, and some do not. If you have certain cancers, hormones might not be safe for you. Your healthcare provider can help you find the best option. You might need to try several treatments before you find the right one.

Bone health

Certain types of cancer and certain cancer treatments can lead to bone thinning or bone loss in women and men.

A bone density scan measures the strength of the bone by looking at the amount of calcium it contains. Usually the scan will focus on your hip or lower spine. Depending on how low your bone mineral density is, your doctor may diagnose osteopenia or osteoporosis. Osteopenia is mild bone loss.

Osteoporosis is the most common type of bone disease. It develops when the body breaks down more bone tissue than it can replace. As a result, bones become weak and fragile. This makes them more likely to fracture or break. Treatment for bone loss often involves the use of bone-modifying drugs. These drugs slow the rate of bone thinning. They may also reduce new bone damage and promote healing.

To keep your bones as strong as possible:

- Do exercises where you support your own body weight, such as walking for 20 to 30 minutes each day. Ask your healthcare provider what exercises you should do.
- Maintain a healthy weight.
- Take calcium, vitamin D, or both. Your provider may do a blood test to check if you have enough vitamin D in your blood. If not, they can tell you how much to take.
- Take medicine to help make your bones stronger.



Practical Matters

Along with treatment, actively manage workplace issues, insurance, finances, and life-planning.



It is important for people to understand all of their rights and options to best navigate many of the systems that are relevant after a cancer diagnosis, such as work, disability and health insurance, and managing finances. The following content on these topics has been provided by Triage Cancer. Triage Cancer is a national, nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers.



Employment

If you have been diagnosed with cancer or if you are a caregiver for someone with cancer, you may need to figure out how to continue working, take time off, return to work, or even retire. Understanding employment laws may help you navigate these options and make decisions. You will need to learn what federal, state, and local laws may apply to you and your employer, as well as what benefits and policies exist in your workplace. The ways that relevant laws, benefits, and policies work together are similar to puzzle pieces fitting together, however, each person's puzzle looks different, depending on the specifics of their situation.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal law that protects eligible individuals with disabilities from discrimination at work. Title I of the ADA defines a disability as a “physical or mental impairment that substantially limits a major life activity.” Major life activities include breathing, walking, talking, thinking, sleeping, and the operation of major bodily functions. The ADA provides protections during all phases of employment (including during the job application process) and when all employment-related decisions are being made, including hiring, firing, pay, benefits, promotions, job assignments, bonuses, training opportunities, and leaves of absence.

You are protected against discrimination at work if: you currently have a disability; you have a history of having a disability; your employer regards you as having a disability; or you have a family, business, social, or other relationship with a person with a disability (e.g., you are a caregiver). If you currently have a disability or a history of a disability you are also entitled to reasonable accommodations.

What are reasonable accommodations?

According to the ADA, “an accommodation is any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities.” Reasonable accommodations are anything that can help you continue to do your job, return to work, or take time off, such as:

- Changing work schedule (e.g., flex time, additional breaks, extended leave).
- Changing work space (e.g., telecommuting, ergonomic chair, hand controls on cars, a different office).
- Using technology (e.g., tablet, smart phone, screen reading software, speak-type software).
- Changing workplace policies (e.g., allowing an employee with a scar to wear a scarf or hat, allowing more breaks).
- Shifting non-essential job duties to other employees.
- Moving to a vacant position, if one is available.

The reasonable accommodations that will work best for you will depend on the side effects that you are experiencing, your job responsibilities, and your workplace. If eligible under the ADA or a state fair employment law, an employer must provide a reasonable accommodation, however, an employer does not have to accommodate you if they can show that the accommodation you are requesting would be an undue hardship or would pose a direct threat.

Asking for a reasonable accommodation

The ADA does not require that you ask for an accommodation from a specific person, however, it is a good idea to check your employer's policies, often found in the employee handbook, to see if your employer has a specific process to request an accommodation. You do not have to specifically mention the ADA or use the words "reasonable accommodation." Your request does not need to be in writing, but having a written record of your request may be useful for future reference.

Once you make a request, you and your employer should engage in the "interactive process," which involves negotiating and agreeing on an accommodation that is effective for you. Your need for an accommodation may change over time. You and your employer should monitor accommodations to ensure they are still effective. If not, restart the process.

Generally, you should ask for a reasonable accommodation when you realize that you need one to effectively complete your job responsibilities.

Is your request for reasonable accommodations confidential?

Generally, your employer cannot share information about your medical condition or why you have asked for, or received, a reasonable accommodation. But, keep in mind, that if you ask your supervisor for an accommodation, your supervisor may take your request to human resources (HR). And, HR might share information with company leaders as appropriate. If you start with HR, because you do not want your supervisor to know about your medical condition, then HR can only share with your supervisor that you are getting an accommodation, not why. Coworkers may ask why you are receiving an accommodation, but your employer can only share that you are getting an accommodation, not share information about your medical condition.

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law that allows eligible employees to take up to a total of 12 weeks of unpaid, job-protected leave, per year, for their own serious medical condition or for the care of a parent, child, or spouse with a serious medical condition. Caregiving can include helping with activities of

daily living, such as providing basic medical, hygienic, nutritional or safety needs; transportation to and from medical appointments; providing psychological comfort; assisting with housework or paperwork; organizing prescription medication or grocery shopping; and assisting in chores. If you receive health insurance coverage from your employer, your employer must continue to offer you that coverage, under the same terms that were in place before taking leave.

Generally, employees should request FMLA leave as soon as they know they need time off work. Check your employee handbook to see if your employer has a process for requesting FMLA leave.

What can you expect when you return to work from FMLA leave?

When you return from FMLA leave, your employer must reinstate you to the same or an “equivalent” job. An equivalent job is one with the same responsibilities, pay, and benefits as the original job. Your employer can require a medical certification that you are able to return to work, so long as that requirement would be applied to any employee in a similar situation. If at the end of 12 weeks of FMLA leave you are not ready to return to work, you may be able to ask for additional time off as a reasonable accommodation under the ADA.

Disclosure, privacy, and medical certification forms

Choosing to disclose your cancer diagnosis at work is a personal decision. But, should be made only after thoughtful consideration of your privacy rights. Some individuals feel comfortable sharing their diagnosis at work. Others have concerns for a variety of reasons. There is no “one size fits all” answer to disclosure. You have privacy rights relating to your medical information:

- The ADA has specific rules about an employer’s access to your medical information. Prior to receiving an employment offer, potential employers may not ask any questions about your medical condition or general health. After a job offer has been made employers are allowed to ask you questions about your health history or to complete a medical exam, but only if they would be required of anyone entering a similar job. Employers are not allowed to rescind a job offer based on the results of a medical exam, unless the results show that you cannot perform the essential functions of that job, with or without a reasonable accommodation. Once you are working for an employer, you can only be asked to complete a medical exam or questions about your health history, when it is “job-related and consistent with business necessity” or if there is a “direct threat” (e.g., requiring an eye exam for a school bus driver). Your request for an accommodation does not necessarily have to mention a cancer diagnosis, but does need to contain enough information

about your medical condition so the employer can determine if you are eligible. For example, if you are experiencing neuropathy as a side effect, the healthcare provider could focus on discussing the neuropathy on the medical certification form, and not include information about your cancer diagnosis.

- Your employer is entitled to medical certification from a healthcare provider to show you are eligible for FMLA leave. However, your employer doesn't necessarily need to know about your cancer diagnosis if you don't want to share that information. Be careful of medical certification forms created by employers, which may request more information than they are entitled to, such as a specific diagnosis. The U.S. Department of Labor has model forms that can be used for guidance as to what information an employer can request. Under the FMLA, there are multiple healthcare providers who can complete the form, including primary care physicians or clinical social workers.

Disability Insurance

If you have been diagnosed with cancer and are undergoing treatment, you may find that you are no longer able to work and earn a living the way that you did before your diagnosis. Disability insurance may provide you with income if you are unable to work because of your medical condition. Disability insurance benefits are offered by the federal government, some state governments, or through a private insurance company.



Federal disability insurance

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are federal programs that provide financial assistance to people with disabilities who are unable to work because of their medical conditions. Both are administered by the Social Security Administration (SSA). If you qualify for benefits, you must meet the SSA's definition of disability: You cannot do your job; and you cannot adjust to a new job; and your disability has, or is expected to, last for at least one year or to result in death.

State disability insurance

California, Hawaii, New Jersey, New York, and Rhode Island, plus the territory of Puerto Rico, offer state short-term disability programs that last from six to twelve months.

Private disability insurance

You can also purchase short-term and/or long-term disability insurance directly from a private insurance company. Private disability insurance can also be offered by your employer as an employee benefit.

Other benefits

If you lose your job, you may be eligible for unemployment benefits in your state. Caregivers may be eligible for state paid leave programs, if they need to take time off as a result of their caregiver responsibilities.

Health Insurance

There are a few health insurance terms that you should understand:

Premium	What you pay each month to have coverage.
Annual deductible	The fixed dollar amount you have to pay out-of-pocket each year, before your health insurance policy kicks in.
Co-payment	A fixed dollar amount you pay when you get medical care. For example, you might have a \$20 co-payment to visit the doctor's office; you might have a \$40 co-payment to see a specialist.
Co-insurance (aka cost-share)	A percentage difference in what the insurance company pays for your medical expenses and what you pay. For example, if you have an 80/20 plan, the insurance company pays 80% of your medical expenses and you pay 20% of your medical expenses, after paying your deductible.
Out-of-pocket maximum	A fixed dollar amount that is the most you have to pay out-of-pocket for medical expenses during the year. Your out-of-pocket maximum depends on your plan. Once you reach your out-of-pocket maximum, your insurance pays 100% of your medical expenses for the rest of the year. Generally, you reach your out-of-pocket maximum by paying your deductible, plus any co-payments, plus any co-insurance payments that you make during the year. Some employer-sponsored plans may carve out expenses from the out-of-pocket maximum (e.g., co-payments won't count towards your out-of-pocket maximum).

Finding the right health insurance plan can feel overwhelming. There are a few key things to consider when picking a health insurance plan:

- What will the plan actually cost me? What premium, deductible, co-pays, co-insurances and out-of-pocket maximum does the plan have?
- Are my healthcare providers and facilities included in the plan's network?
- Does the plan cover my prescription drugs and the pharmacies I use?

When comparing plans, it can be tempting to just choose the one with the lowest monthly premium. But, to figure out the total cost for the year in a worst-case scenario, including your out-of-pocket expenses, you have to do some math: *(Plan's monthly premium x 12 months) + Plan's out-of-pocket maximum = Total annual cost*

You should review your options every year to ensure your plan meets your needs.

Health insurance options

The health insurance options available to you depend on where you live, your age, your employment, your income level, and a number of other factors. If you lose employer-sponsored coverage, you may have a number of options for comprehensive health insurance coverage, even if you have a pre-existing medical condition such as cancer. These options include a marketplace plan, COBRA, another group health plan, Medicaid, or Medicare. Because you may be eligible for more than one of these options, it is important to compare your options to determine which plan is best for you:

- **Health Insurance Marketplaces.** The Patient Protection and Affordable Care Act (ACA) created a new way to find and buy private health insurance coverage for individuals and families: state health insurance marketplaces. These marketplaces have been compared to an insurance shopping mall. The marketplaces for most states are operated by the federal government at HealthCare.gov. Some states run their own marketplaces. There are real benefits to shopping for coverage through the marketplace, including: standardized plans; consumer protections; and financial assistance based on your household income level. Marketplace open enrollment periods may vary from year to year. States that run their own marketplaces may have their own open enrollment periods. If you lose coverage or have a life-changing event (e.g., losing employer-sponsored health insurance), you may qualify to enroll during a special enrollment period.
- **COBRA** is a federal law that allows eligible employees to keep their existing employer-sponsored health insurance plan for 18 to 36 months after experiencing a "qualifying event," such as losing or leaving your job. There are also a few times when COBRA coverage may end early, such as when an employer stops offering coverage to all employees or when an employer goes out of business.

- **Another group health plan.** You may be eligible for a special enrollment period to move to a group plan that is available through another job that you might have, your spouse’s group plan, or a parent’s plan (if you are under 26). Check the other employer’s plan for rules.
- **Medicaid** is a federal health insurance program that provides coverage to individuals with low income levels. Even though Medicaid is a federal program, each state runs its Medicaid program differently. If you live in a state that expanded its Medicaid program under the ACA and you have a household income under 138% of the federal poverty level (FPL), you may be eligible for Medicaid. If you live in a state that has not expanded Medicaid, eligibility is based on having a low income level, having a low resource level (e.g., assets), and meeting another category of eligibility, such as receiving SSI. Currently, 40 states and Washington, DC, have expanded their programs and 10 states have not. Medicaid applications are accepted year-round.
- **Medicare** is a federal health insurance program that provides coverage to individuals who are 65 or older, have collected SSDI more than 24 months, or have been diagnosed with end-stage renal disease or ALS. Medicare coverage is broken down into 4 parts, each of which has different costs:
 - › **Part A:** Hospital Insurance. Includes hospital care, skilled nursing facilities, nursing homes, hospice, and home healthcare.
 - › **Part B:** Medical Insurance. Includes outpatient care from doctors, preventive care, lab tests, mental health care, ambulances, and durable medical equipment.
 - › **Part D:** Prescription Drug Coverage. Plans are sold by private insurance companies and you have different options based on where you live.
 - › **Part C:** Advantage Plans. An alternative to Parts A and B, it includes the care covered under A and B, and usually Part D. You can choose a PPO or HMO plan run by a private insurance company.

Acronyms used in this section:

ACA	Affordable Care Act
ADA	Americans with Disabilities Act
COBRA	Consolidated Omnibus Budget Reconciliation Act
FMLA	Family and Medical Leave Act
EOB	Explanation of Benefits
EPO	Exclusive Provider Organization
FPL	Federal Poverty Level
FSA	Flexible Spending Account
HMO	Health Maintenance Organization
HR	Human Resources
HSA	Health Savings Account
PPO	Preferred Provider Organization
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

Parts A and B together are referred to as Original Medicare. Someone with Original Medicare may choose to buy a supplemental Medigap plan to help with out-of-pocket costs. Plans are labeled as A through N, and each plan with the same letter must offer the same basic benefits in most states. The premiums and deductibles vary by plan. If you have Medicare Part C, you are not eligible to buy a Medigap plan.

People who have difficulty affording Medicare, due to low incomes and low resources, may be eligible for a Medicare Savings Program and/or the Extra Help Program. In addition, some people are eligible for both Medicare and Medicaid.

Finances

Managing medical bills

Cancer is expensive. But knowing some key tips on how to manage your medical bills can help you avoid unnecessary expenses.

- **Have the right insurance.** You many tend to look only at a plan's monthly cost when choosing a health insurance policy. However, you should also look at the out-of-pockets costs that you have to pay when you get medical care, such as co-payments, deductibles, and out-of-pocket maximums. You also need to make sure the plan covers your providers, hospitals, and prescription drugs. Review your health insurance coverage each year to make sure that you have the best coverage for your current needs.
- **Discuss costs with your healthcare team before treatment.** They may have suggestions for reducing costs; for example, grouping healthcare appointments together to avoid extra co-payments for office visits. You might also be able to negotiate your medical bill before you get care. Ask for upfront pricing for all nonemergency tests and procedures and ask if there are discounts available.
- **Get pre-authorization.** Many health insurance companies require you to obtain prior approval (also called pre-authorization) before you get medical care. If you don't get the pre-authorization, your health insurance company might deny your claim. Ask your healthcare team to check if you need pre-authorization before getting care. If your healthcare team does not request a pre-authorization for you, you are responsible for getting approval from your insurance company. Also, even if you receive approval, it does not guarantee that your insurance will cover your care.
- **Go to in-network providers.** To be a part of a plan's network, doctors and facilities contract with the plan and agree to accept a specific rate for their services under the plan. These doctors and facilities are considered "in-network." Doctors and facilities that do not have a contracted relationship with an insurer are considered "out-of-network." Some PPO plans have limited coverage for out-of-network providers (e.g., 50%). Most HMO and EPO plans pay 0% for out-of-network providers.

- **Keep track of your out-of-pocket payments.** While your insurance company usually keeps track of what you have paid for out-of-pocket medical care and may list that on each Explanation of Benefits (EOB) you receive, it can be helpful to keep track on your own. Mistakes happen, and you don't want to pay more than you are required to under your plan. Also, when you visit a provider, you may be asked to pay a co-payment when you check in. If you have an insurance plan that includes your co-payments in your out-of-pocket maximum, your provider may not know that you have already reached your out-of-pocket maximum and, therefore, aren't responsible for paying any more co-payments for the rest of your plan year.
- **Leverage out-of-pocket maximums.** If you've reached your maximum for the year, consider addressing any other healthcare needs you have, rather than waiting until the new plan year, where you will have to meet your deductible and out-of-pocket maximum again.

Reviewing your medical bills

Once you've gotten a medical bill, it's important to review it to make sure it's accurate. Don't be afraid to ask your providers to explain codes or descriptions of services you received. Small errors, such as a wrong number or code, can make a big difference in your bill. Ask for an itemized list of charges, request a copy of your medical records and pharmacy ledgers, and check that everything matches up. If you need help managing your medical bills, consider asking family and friends for help. They can open mail, match EOBs to bills, and put payment due dates on your calendar.

Appealing denials

At some point during cancer treatment, you may experience a denial of coverage from an insurance company, whether for an imaging scan, prescription drug, treatment, procedure, or genetic test. And most of us take "no" for an answer. But those who don't accept the denial and file an appeal may actually win and get coverage for the care prescribed by their healthcare team. There are different rules for filing appeals depending on the type of health insurance coverage that you have. Medicare, Medicaid, military and Veterans plans all have specific rules. If you have a private individual health insurance policy or a health insurance policy through work, you generally have two chances to appeal a denial of coverage, via an internal appeal and an external appeal.

Getting organized

There are lots of tools available to keep track of your medical bills, EOBs, medical records, and other paperwork related to your medical care. But the key is to use the tool that makes it easier for you to stay organized, whether that is a box with file folders or a 3-ring binder, such as **Bag It's My Companion Guidebook**. You should also keep track of any communications that you have with your provider and health insurance company. One reason it is important to stay organized is that

tracking all of your expenses related to your medical and dental care (including meals, lodging, and travel expenses related to medical care) could save you money. These expenses might be tax-deductible, or possibly paid for through a Health Savings Account (HSA) or Flexible Spending Account (FSA).

Paying your medical bills

If you receive a medical bill that you are unable to pay, it is important not to ignore it. Consider contacting your provider to ask for more time, or see if your provider would be willing to negotiate a payment plan or accept a lower lump-sum payment. It is also important not to wait too long to contact your provider about an unpaid medical bill. Contacting your provider before unpaid bills get sent to collection agencies can help protect your credit score.

Be careful when you're considering paying medical bills with credit cards; they usually have high interest rates, and you could end up spending more than necessary. Be careful when considering taking out a home loan to pay off medical debt. Using your home as collateral transfers the debt from being unsecured to secured, which means that the lender could take your home if you are unable to make payments. You may be able to qualify for financial assistance programs to help offset the cost of your medical bills.

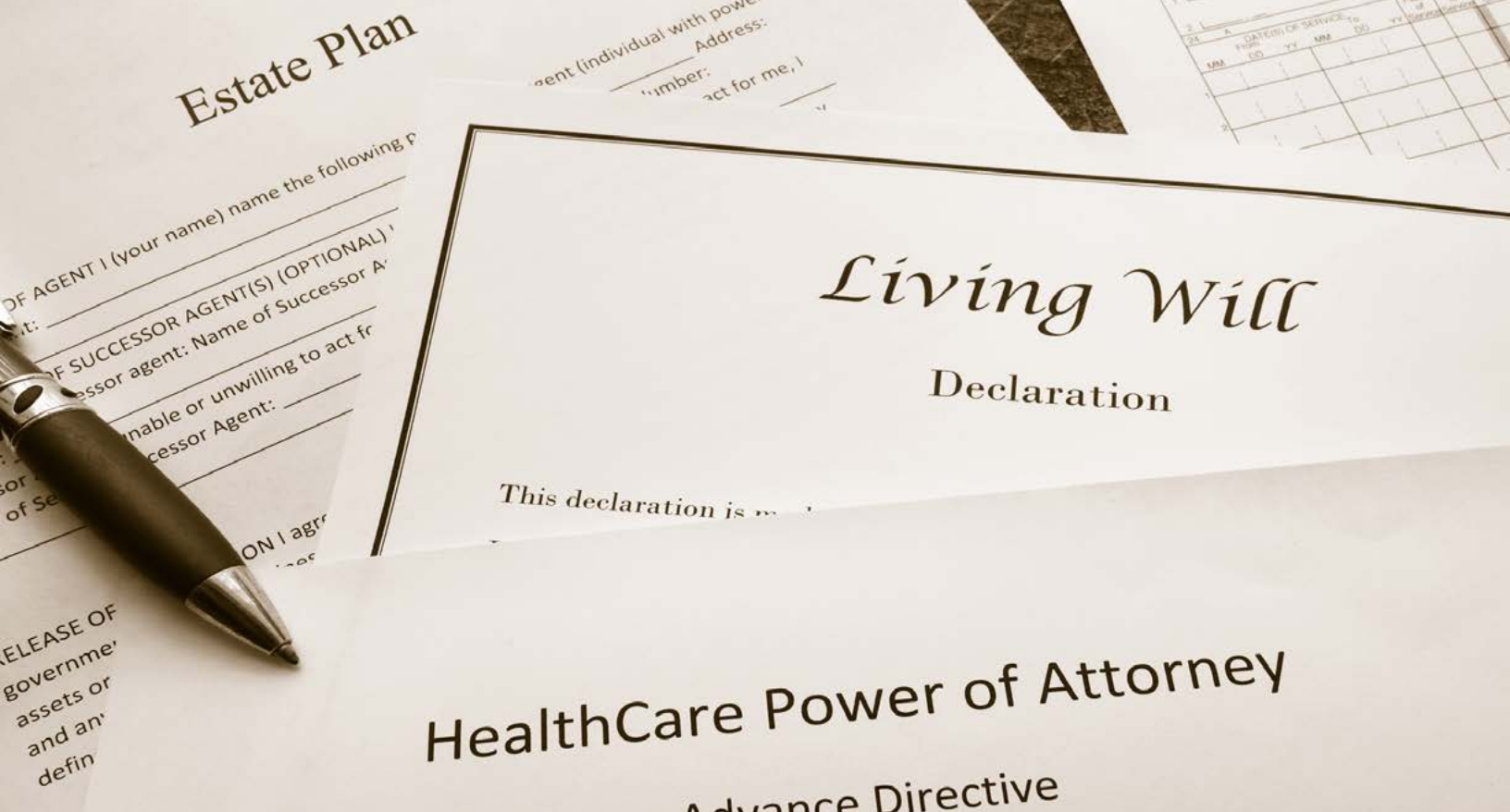
Finding financial help

It can be helpful to keep an open mind when thinking about financial assistance. Although you may need one type of assistance, if you are able to get assistance in a different category, funds you have saved can be shifted. For example, if you have money for your gas bill, but not your rent, you may be able to get utility assistance and shift those funds to help you pay your rent. Be creative when looking for help. Consider the following:

- State, county, or local government financial assistance programs (e.g., 2-1-1, utilities and transportation assistance, Supplemental Nutrition Assistance Program, Housing Choice vouchers)
- Private financial assistance programs in the healthcare community
- Private financial assistance programs in the cancer community
- Pharmaceutical company assistance programs
- Healthcare industry assistance programs (for help accessing items other than prescription drugs)
- Local service organizations and faith-based organizations
- Crowdfunding (i.e., asking people to donate money using an online platform)

Scan for more information





Advance Care Planning

Advance healthcare directives

As a self-advocate, advance care planning you do today gives voice to and guides the kind of medical care you want tomorrow - regardless of your current health or your prognosis. Advance healthcare directives (usually in the form of a written legal document) are used to relay your care wishes, preferences and values to your healthcare team and loved ones in the event you are unable to speak for yourself.

A **living will** (also called healthcare instructions) specifies the type of medical care you do or do not want in case you are unable to speak or make decisions for yourself. This could include medical tests, procedures, life-sustaining measures, treatments, or medications to be used at the end of life. Know that if you choose not to receive treatment or to stop treatment to control your cancer, palliative care, including pain management, continues while still honoring your values and goals. (See **Palliative care** on page 78.)

A **power of attorney for healthcare** (also called healthcare proxy) names another person (called an agent, proxy, surrogate) you select to make healthcare decisions for you if you are unable to do so. This person is someone you trust who understands your wishes, is qualified, and is willing and able to serve in this role for you.

Don't wait to fill out your advance directives, even if the conversations are difficult and decisions are hard to make. Let your loved ones know you are making choices for yourself now so they do not have to do so later, which will bring some peace of mind for everyone. You can always revise the documents if your choices or situation changes.

The advance healthcare directive document names, forms, and requirements vary by state. Your healthcare team may be able to provide you with the forms and help you complete them. In some states only witnessing of your signature is required and a notary and/or lawyer are not required. A few states consider video and digital advance directives to be legally valid.

Once completed, provide copies of your signed documents to your healthcare team, hospital, caregivers, family, as well as the agent named in your healthcare power of attorney and discuss them. Keep the original in a safe place at home. If you make changes, be sure everyone gets a new copy and destroys the old one.

Scan for more information



Visit [BagItCancer.org/resources](https://www.BagItCancer.org/resources) for more information on creating advance healthcare directives and forms for every state.

It's important to talk with your loved ones about your wishes. If you need support, ask your doctor or another trusted member of your healthcare team to help you have this conversation.

Other legal documents to consider creating

A **will** (different from a living will) describes what you would like to have happen to your property and assets when you die. It can appoint a legal guardian to care for your minor children, if necessary.

Should you become unable to handle your own financial matters, a **financial power of attorney** names a trusted adult (such as a family member or a friend) to make these decisions and pay your bills for you.

After Active Treatment Ends

A New Phase In Self-Advocacy

When active cancer treatment ends, it is important to monitor your physical, mental and emotional well-being and to continue to be proactively involved in your healthcare.

You may recognize that your needs, priorities, and values in your life have now changed. As you make critical decisions about your future medical care and self-care, adjust the skills, practices and methods you relied upon to this point to continue to communicate them to your healthcare team and others.

The next few pages can help guide you through some of the common concerns of this phase of survivorship and how to ensure you receive the best care and support possible.

Follow-up Care

Follow-up care, or seeing a doctor for regular medical checkups, is critical for your well-being. Who you see for follow-up cancer care is a decision that your oncologist will discuss with you. It is based on many factors, including what care you need and who you feel comfortable with. How often you have follow-up appointments will depend on your particular cancer type, treatment, and overall health. Be sure to keep all of your scheduled appointments and follow the doctor's instructions for testing ordered or medications prescribed.

It's important to be aware of any changes in your health between scheduled visits. Report any problems to your doctor immediately. They can decide whether the problems are related to the cancer, the treatment you received, or an unrelated health issue.



Your doctor will examine you and review your medical history since your last visit. They may order lab work and other testing to monitor side effects and check to see if your cancer has returned or spread.

If your follow-up appointments for cancer care are with your oncologist, you will also need to schedule regular medical checkups with your primary care or family doctor and other specialists caring for you. Keep them updated with your oncology visits, and give them a copy of your Treatment Summary and Survivorship Care Plan.

What to tell your doctor during follow-up visits

During follow-up visits speak openly about any physical or emotional concerns you are having. It's normal to have fears about every ache and pain you have, but they may just be problems that your doctor can easily address.

Questions to ask your healthcare team about follow-up care:

1. Can I have a Treatment Summary and Survivorship Care Plan?
2. What follow-up care do I need? With whom and how often?
3. Do I need any follow-up tests? If so, how often?
4. What symptoms or side effects should I report and to whom?
5. Are there late or long-term side effects or health issues I should be aware of?
6. Are there helpful survivorship programs or resources you can recommend for me, my caregiver, and family?

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Discuss with your healthcare team which complementary therapies might help you manage any lingering side effects of treatment and improve your quality of life.

Discuss with your doctor:

- Any new or ongoing physical problems that interfere with your daily life, such as fatigue; problems with bladder, bowel, or sexual function; having a hard time concentrating; memory changes; trouble sleeping; or weight gain or loss.
- Any new medicines, vitamins, herbs, or supplements you are taking.
- Changes in your health or your family medical history.
- Any emotional concerns you are having, such as anxiety or depression.

Use the forms in *My Companion Guidebook* to write down your questions and updates, and to create any logs of symptoms, side effects or other details you want to track. Make a copy to give to your doctor at your next appointment.

Treatment Summary and Survivorship Care Plan

Near the completion of your cancer treatment or as you transition to extended treatment, a member of your healthcare team should prepare a Treatment Summary and Survivorship Care Plan for you. This important document summarizes your cancer diagnosis and treatment and includes a plan for your future follow-up care. It should be shared with your other healthcare providers to help them better manage your recovery and overall health. Keep a copy in *My Companion Guidebook*. The Survivorship Care plan should be updated and redistributed as your health changes.

Your healthcare team may use their own forms or a template available from other organizations such as the American Society of Clinical Oncology (ASCO) or The OncoLife™ Survivorship Care Plan. You may need to schedule a separate appointment to review this document and discuss any questions you have. This could be with a navigator or other member of your healthcare team.

Request this document if your healthcare team does not routinely provide this for their patients. Visit BagItCancer.org/resources for more information and templates.

The image shows a stack of three overlapping forms. The top form is titled "Follow-up Care Plan" and includes sections for "General Information", "Health Care Providers", "Diagnosis", "Treatment Summary", and "Familial Cancer Risk Assessment". The forms contain various checkboxes and text input fields for patient information, treatment details, and risk factors.

The Treatment Summary includes:

- Date of diagnosis; type, stage, cancer grade.
- Treatments received (surgeries, chemo, radiation, other therapies, clinical trials) and tests performed with dates, location, responses to treatment, ongoing treatments.
- Any complications or side effects of treatment experienced.
- Contact information for doctors and healthcare team.
- Biomarker/genetic test results.
- Supportive/palliative care received.

The Survivorship Care Plan includes:

- The state of your current health as of the date of the survivorship plan, any ongoing treatments, and any side effects that you are experiencing at that time.
- A schedule for future surveillance and screenings (labwork, tests, scans), checkups needed, and by whom.
- Potential late and long-term side effects and surveillance of new symptoms.
- Recommendations for healthy living—physical and emotional.

Common Emotions After Active Treatment Ends

At the end of active treatment, a patient's safety net of regular, frequent contact with the healthcare team ends. Survivors may experience:

- Relief that treatment is over.
- Uncertainty about the future.
- Loss of usual support.
- Increased anxiety.
- Fear of recurrence, that the cancer will come back after treatment.
- Guilt about surviving, having lost friends and loved ones to cancer.
- Physical, psychological, sexual or fertility problems.
- Relationship struggles.
- Discrimination at work.
- A social network that now feels inadequate.

Coping with Fear of Recurrence

After treatment ends, one of the most common concerns survivors have is that the cancer will come back. If this does happen, it is called cancer recurrence. Having a fear of recurrence is very normal. The main way to reduce the chance of cancer recurrence is to have a good follow-up care plan, also called a survivorship care plan, with a healthcare team you trust. Knowing your health is being closely monitored can help reduce your fear of recurrence. If fear of recurrence persists, there are additional things you can do to help control this fear and reduce its effect on your daily life.

How to cope with the fear of cancer recurrence

Living with uncertainty is never easy. It is important to remind yourself that fear and anxiety are normal parts of survivorship. Worrying about cancer coming back is usually most intense the first year after treatment. This worry usually gets better over time, and you should let your healthcare team know if it does not. Here are a few ideas to help you cope with the fear of recurrence:

- **Recognize your emotions.** Many people try to hide or ignore “negative” feelings like fear and anxiety. Naming them will help you think about ways to cope with them. It often helps to talk about your fears with a trusted friend, family member, or mental health professional. Talking out loud about your concerns may help you figure out the reasons behind your fears. This might include the fear of having to repeat cancer treatment, losing control over your life, or facing death. You can also try writing down your thoughts, such as keeping a journal, or expressing yourself through art or music.

- **Do not ignore your fears.** Telling yourself not to worry or criticizing yourself for being afraid will not make these feelings go away. Accept that you are going to experience some fear, and focus on ways to manage the anxiety. Be aware that your anxiety may temporarily increase at specific times. For instance, when you need follow-up imaging scans, you may experience “scanxiety.” Other times this fear often increases includes follow-up lab tests or doctor visits, the anniversary of your diagnosis, or a time when someone else gets a new cancer diagnosis. Sometimes, you may worry about things that are unlikely to happen. Talking with your healthcare team about your worries can help by discussing the likelihood of your concerns together.
- **Join a support group.** Many cancer survivors find joining a support group to be helpful. Support groups offer the chance to share feelings and fears with others who understand. They also allow you to exchange practical information and helpful suggestions. The group experience often creates a sense of belonging that helps survivors feel less alone and more understood.
- **Make healthy choices.** Healthy habits like eating nutritious meals, exercising regularly, and getting enough sleep help people feel better both physically and emotionally. Avoiding unhealthy habits, like smoking and excessive drinking, helps people feel like they have more control over their health.
- **Reduce stress.** Finding ways to manage stress will help lower your overall level of anxiety. Try different ways of reducing stress to find out what works best for you.



Tips to reduce stress include:

- › Spend time with family and friends.
 - › Focus on hobbies and other activities you enjoy.
 - › Take a walk, meditate, or enjoy a bath.
 - › Exercise regularly.
 - › Read a funny book or watch a funny movie.
- **Be well informed.** There is some research about the pattern of recurrence for many types of cancer. But no one can tell you exactly what will happen in the future. Your oncologist or another healthcare professional who knows your medical history can tell you about the chances of the cancer returning. They can also tell you what symptoms to look for. Knowing what to expect may help you stop worrying that every ache or pain means the cancer has returned. If you do experience a symptom that does not go away or gets worse, talk with your healthcare team.
 - **Stick with your follow-up care plan.** A main goal of follow-up care is to check for a recurrence of cancer. Recurrence can happen in the weeks, months or even years after your original cancer was treated. Your follow-up care plan may include regular physical examinations and/or tests to keep track of your recovery. Having a regular schedule of follow-up visits can provide survivors with a sense of control. (See **Follow-up Care** on page 62.)

When you may need more help

You might find yourself overwhelmed by fear or anxiety even after your best efforts to cope with it. The following signs may indicate more serious anxiety or depression:

- Worry or anxiety that gets in the way of your relationships and daily activities.
- Fear that prevents you from going to your follow-up care appointments.
- Hopelessness or apathy about the future.
- Not participating in activities you used to enjoy.
- Difficulty sleeping or eating well.
- Trouble concentrating or making decisions.
- Feeling that you have nothing to look forward to.
- Being unusually forgetful.

If you are concerned about anything on this list, talk with your healthcare team. You may also want to consider counseling. Counseling may help you sort through unrealistic and realistic fears and give you tools to reduce anxiety. Working with a counselor can also help determine if you have ongoing symptoms of depression or chronic anxiety that could be relieved by additional support, like medication or psychotherapy.

Feelings of hopelessness may lead to thoughts about suicide. If you or someone you know is thinking about suicide, get help as soon as possible. The 988 Suicide & Crisis Lifeline is available anytime. For English, call 1-800-273-TALK (8255) or call, text or chat 988. For Spanish, press 2.



Relationships

Changes within families and relationships

Cancer often changes the way you relate to your family, partner, and friends, and the way they relate to you. When active treatment is over, some survivors need different types of support than they had before. Some friends may become closer, while others may distance themselves. Families can become overprotective or may have exhausted their ability to be supportive. Relationship problems that may have been ignored before a cancer diagnosis can be brought to the surface. Everyone is changed by the cancer experience in ways they may not even be aware of.

Parenting and family life

Living with and beyond cancer often makes people rethink the way they live their lives, including the way they parent. When active treatment ends, many survivors find that parenting after cancer presents unique challenges. For months or even years, the demands of cancer and treatment may have made it difficult to spend time with your children. The guilt of constantly being away from home or unavailable can trigger a strong desire to just be a “normal parent,” or sometimes even a “super parent,” to make up for that lost time. However, long-term side effects of cancer treatment, such as memory loss, difficulty concentrating, pain, fatigue, or permanent disabilities, can make parenting even more demanding and frustrating. It is important not to compare yourself to other parents during this time. As you adjust to life after treatment, you can only do your best and shouldn't be hard on yourself because of what you might see as limitations.

Sexuality and intimacy

In general, although people are less interested in sex while having cancer treatment and at times of crisis, interest in sex usually improves during recovery and survivorship. However, some survivors may experience changes in their sexual function or sex drive caused by cancer and cancer treatment. Some treatments, even those not directed at the pelvic area or groin, can cause physical side effects that interfere with sexual function. But even other physical changes not directly related to sexual function may affect the way a person feels about his or her body and his or her physical attractiveness, such as losing a testicle or a breast, needing a colostomy or another type of ostomy, losing weight or hair, or having scars or skin changes. Even a person whose body was not outwardly changed by cancer may feel differently about his or her body. All of these changes affect self-image, self-confidence, and a person's sense of attractiveness.

Physical Changes and Side Effects

Managing late and long-term side effects

Most people expect to experience side effects during treatment. However, it is often surprising to survivors that some side effects may linger after treatment, called long-term side effects, or that other side effects may develop months or even years later, called late effects. Other health conditions you may have, such as diabetes or heart disease, may also be made worse by cancer treatment.

These long-term effects are specific to certain types of treatment and usually develop within a defined time. Your doctor will be able to tell you if you are at risk for developing any late effects based on the type of cancer you had, your individual treatment plan, and your overall health.

Late and long-term side effects may include:

- Fatigue.
- Chemobrain.
- Emotional difficulties and mood disorders.
- Lymphedema.
- Chronic pain.
- Anemia.
- Secondary cancer.
- Lung problems.
- Heart problems.
- Peripheral neuropathy.
- Endocrine problems.
- Digestion problems.
- Bone thinning.
- Sexuality and fertility issues.

Physical changes

Some have described survivorship as being “disease-free, but not free of your disease.” What you experience with your body may be related to the type of cancer you had and the treatment you received. It’s important to remember that no two people are alike, so you may experience changes that are very different from someone else’s, even if that person had the same type of cancer and treatment. You may find that you are still coping with the effects of treatment on your body. It can take time to get over these effects.

Questions to ask your healthcare team about late and long-term side effects

1. What can be done to manage any side effects that continue after treatment?
2. What are the most common late and long-term effects that may develop based on my treatment plan?
3. What should I do if I notice a late side effect?
4. What screening tests do you recommend based on my cancer history?
5. Are there other doctors or specialists I should see to monitor for these side effects?

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Supportive Care After Cancer Treatment

After active treatment ends, you may continue to experience some lingering and/or late side effects including pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia. Palliative care specialists can work with you and your oncology team to relieve these symptoms and improve your quality of life. Depending on your cancer and the symptoms you are experiencing, your palliative care team may prescribe medication, physical or occupational therapy, as well as recommendations for nutrition and activity. Some complementary and integrative therapies such as relaxation techniques, massage, and acupuncture may provide relief from physical symptoms in addition to the benefit of emotional and spiritual support. (See **Palliative care** on page 78.)

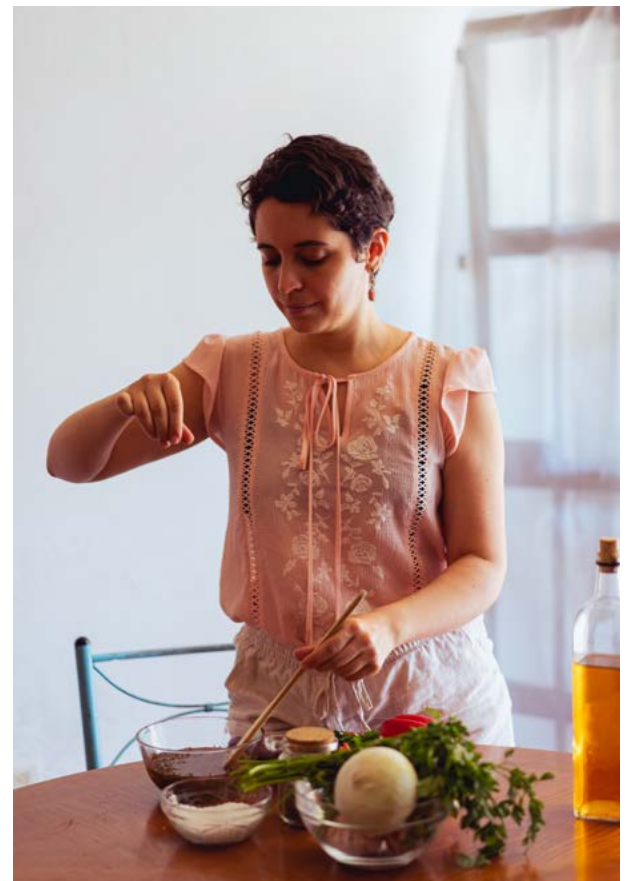
If you have not already been receiving this kind of supportive care, let your healthcare team know what you are dealing with and ask for help. Most insurance plans, including Medicare and Medicaid, cover at least some services.

Healthy Lifestyle After Cancer Treatment

After cancer treatment, many survivors want to find ways to reduce the chances of their cancer coming back. Some worry that the way they eat, the stress in their lives, or their exposure to chemicals may put them at risk for recurrence, a second cancer, or other health issues. Cancer survivors find that this is a time when they take a good look at how they take care of themselves and how they might live a healthier life. Some general tips for all cancer survivors include:

- **Quit smoking.** Smoking after cancer treatment can increase the chances of getting cancer at the same or a different site.
- **Cut down on how much alcohol you drink.** Drinking alcohol increases the risk of certain cancers and cancer recurrence.
- **Maintain a healthy weight.** Eating well and staying active can help you reach a healthy weight and stay there.
- **Eat well.** A healthy and balanced diet is important for overall wellness.
- **Exercise and stay active.** Research suggests that staying active after cancer may help lower the risk of recurrence and lead to longer survival. In addition, moderate exercise (walking, biking, swimming) for about 30 minutes every day—or almost every day—can:
 - › Reduce anxiety and depression.
 - › Improve mood and boost self-esteem.
 - › Reduce fatigue, nausea, pain, and diarrhea.

Be sure to talk to your doctor before making any changes in what you eat and how you exercise. Ask your healthcare team which complementary therapies might be helpful to you to relieve stress and other symptoms or side effects you may be experiencing. (See **Supportive care** on page 34.)



[6]

Long-Term Treatment and Advanced Cancer

Many people with cancer can be cured with primary treatment. Others have cancer that never goes away completely with treatment. But often it can be controlled with ongoing treatment for months or years.

Long-Term Treatment

Similar to the approach with such chronic illnesses as type 1 diabetes, the goal of long-term treatment is to help patients live as well as possible for as long as possible. There are different situations and different types of cancer that might benefit from long-term, extended cancer treatment. For example:

- **To prevent cancer from returning (recurrence).** Some people whose cancer has been cured may need ongoing treatment to keep it from coming back.
- **To put cancer in remission and maintain and control cancer progression.** Doctors may choose a long-term treatment to help stop the disease from growing, spreading, or progressing. This is also called maintenance treatment.
- **To manage advanced cancer.** Metastatic cancer may be treated over the long term. Metastatic cancer means that the cancer has spread to a different part of the body from where it started. With advances in research, doctors can now treat some types of metastatic cancer for much longer periods of time, even when the disease cannot be cured.



Your doctor may recommend long-term or life-long treatment to help you live with cancer. Long-term treatments can include surgery, radiation therapy, and systemic therapies like chemotherapy, targeted therapy, hormone therapy, and immunotherapy. You may receive the same type of systemic therapy initially used to treat your cancer. Or, a different drug or combination of drugs may be used to treat cancer. Your doctor may also suggest you join a clinical trial for a specific long-term treatment. The type of long-term treatment you receive depends on many different factors, including your cancer type, location, stage, your age, and your general health.

During your treatment period, your cancer may stay the same over time. This means it is controlled. If the therapies stop working or they cause side effects, also called toxicity, that are unacceptable to you, your doctor may change the dose or stop the medication. Treatment may be stopped if the cancer is in remission and then restarted if it starts growing again. It is also possible for the cancer to go through cycles of growing and shrinking. If cancer continues to grow or spread, a different treatment may be recommended. In general, cancer treated in this way may change over time, but it does not go away completely.

Questions to ask your doctor about long-term treatment

Regular and open communication with your healthcare team is important when you have long-term cancer treatment.

Consider asking them the following questions:

1. What are my extended treatment options? What is the goal of each treatment?
2. How will we know if the extended treatment is working?
3. What clinical trials are open to me? Where are they located, and how do I find out more about them?
4. What side effects can I expect? How can they be managed?
5. How will this treatment affect my daily life? Will I be able to work and perform my usual activities?
6. How long will I continue to receive extended treatment?
7. What follow-up tests will I need? How often will I need them?
8. If I have concerns about the costs of long-term cancer care, who can help me?
9. Where can I find emotional support for me and my family?

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Follow-up Care and Maintenance

Seeing your oncologist for regular medical checkups is critical for your well-being. The frequency of follow-up appointments will depend on your particular cancer type, your treatment and your overall health. Your doctor will examine you and review your medical history since your last visit. They may order bloodwork and other testing to monitor side effects and the status of your cancer. For some people this will include imaging, like scans. It is also important to continue receiving regular medical care from your primary care/family doctor and other specialists. Keep them updated with your oncology visits and give them a copy of your Treatment Summary and Survivorship Care Plan. (See **Treatment Summary and Survivorship Care Plan** on page 65.)

Coping with cancer while receiving long-term treatment

It is normal to feel angry, scared, anxious, or sad about cancer that needs long-term treatment. Talking about your feelings is important, even when treatment works well. Ask your healthcare team for resources that can help you cope, such as:

- Talking with a counselor.
- Joining an in-person or online support group.
- Finding a support buddy through a cancer organization.
- Learning relaxation and stress management techniques. Meditation, yoga or deep breathing can help.

If you are not finding relief or are struggling with distress or depression, seek help right away from your healthcare team. (See **Depression** on page 29.)

Advanced Cancer

Although cancer treatments continue to advance, not everyone recovers from cancer. Sometimes a cure or long-term remission, a period with no signs of cancer, becomes unlikely or isn't possible. Doctors call this stage of disease advanced, end-stage, or terminal cancer. Even if a cancer can't be cured, it can still be treated. People with advanced cancer continue to have treatment options. They may be able to maintain a good quality of life for months or even years. Your doctor may suggest one or more different types of treatment, including:

- Standard treatment (e.g. chemotherapy, radiation therapy). (See page 14.)
- Palliative (supportive) care. (See page 78.)
- Hospice care. (See page 80.)
- Clinical trials. (See page 17.)



Talking about your advanced cancer

Once you are diagnosed with advanced cancer, or your disease has progressed to this point, you will need to discuss future steps and what to expect with your healthcare team and your loved ones. Having these talks may not be easy. But knowing your options and sharing them with others will make it easier for you to move forward with your care. Here are just a few topics you may want to discuss with your doctor or other members of your healthcare team:

- **Pain or other symptoms.** Be honest and open about how you feel. Tell your doctor if you have pain and where. Let them know the medications you are taking and how you are taking them. Also tell them what you expect in the way of pain relief.
- **Communication.** Some people want to know details about their care. Others prefer to know as little as possible. Some patients want their family members to make most of their decisions. What would you prefer? Decide what you want to know, how much you want to know, and when you've heard enough. Choose what is most comfortable for you, then tell your doctor and family members. Ask that they follow through with your wishes. (See **Communicating with Your Healthcare Team** on page 7.)

- **Family wishes.** Some family members may have trouble dealing with cancer. They don't want to know how far the disease has advanced or how much time doctors think you have. Find out from your family members how much they want to know, and tell your healthcare team their wishes. Do this as soon as possible. It will help avoid conflicts or distress among your loved ones.

Remember that only you and those closest to you can answer many of these questions. Having answers to your questions can help you know what to expect now and in the future.

Questions to ask your healthcare team about advanced cancer

Whether you've just been diagnosed, or the standard treatment isn't working, it's important to ask your healthcare team what to expect in the future. Studies show that patients who have these discussions with their doctor have a better quality of life than those who don't. The more information you have, the better decisions you and your loved ones can make about how you want to move forward with your care.

Questions to ask your doctor about your cancer and treatment choices

1. How long can I live with my advanced cancer?
2. Are there tests I should have now to find out more about my cancer?
3. What's the best we can hope for by trying another treatment? What's the goal?
4. What are my treatment choices? Which do you recommend for me and why?
5. Would a clinical trial be right for me?
6. What kind of care will I receive to keep me comfortable if I decide not to have active treatment for my cancer?

Questions to ask your doctor about symptoms and side effects

1. What are the possible side effects and how likely are they?
What else should I know about this treatment?
2. How can I manage the symptoms of my advanced cancer or the side effects of its treatment?
3. Can you refer me to a palliative care specialist to help me cope with my side effects?

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Decisions for care when cancer is terminal are very personal and it's natural to want to do all you can. But you should weigh these feelings against the risks and benefits of available treatments as well as your own feelings. You should ask all the questions you need to. If you choose not to go through more active cancer treatment, you can continue to receive supportive care in order to keep you as comfortable as possible.

Coping with advanced cancer

Learning you have advanced cancer triggers intense emotions, including anger, fear, sadness, and regret. It is normal for you to mourn the loss of your abilities. You may grieve for the loved ones you will leave behind and the days you will not have. You may also find it hard to believe or accept that your disease is incurable, causing feelings of anxiety and uncertainty. Talking about your feelings and concerns with family, friends, and caregivers can help bring you comfort. Patients and their families shouldn't be afraid to tell doctors, nurses, and social workers how they feel. The healthcare team is there to help. Many team members have special skills and experience to make life easier for people with advanced cancer and their families. In addition to providing emotional support and education, your doctor may prescribe medications to help with anxiety or depression. Your doctor may also refer you to other community resources, including a social worker, counselor, psychologist, psychiatrist, or support group.

Feelings of hopelessness may lead to thinking about suicide. If you or someone you know is thinking about suicide, get help as soon as possible. The 988 Suicide & Crisis Lifeline is available 24 hours a day, 7 days a week. For English, call 1-800-273-TALK (8255) or call, text or chat 988. For Spanish, press 2.

Palliative/Supportive Care and Hospice Care

The aim of standard treatment and some clinical trials is to shrink tumors or stop them from growing. This is called disease-directed treatment. The aim of palliative, or supportive, care is to improve quality of life and maintain independence by reducing symptoms, managing pain, and supporting patients and their families. The aim of hospice care is to help the patient approach the end of life with peace, respect, and dignity, and it includes palliative care.

Private health insurance usually covers palliative care services. Medicare and Medicaid also pay for some kinds of palliative care.

Palliative care specialists work as part of a multidisciplinary team that may include doctors, nurses, registered dietitians, pharmacists, chaplains, psychologists, and social workers. The palliative care team works with your oncology care team to manage your care and maintain the best possible quality of life for you.

Your oncologist (or a member of your oncology care team) is the first person you should ask about palliative care. They may refer you to a palliative care specialist, depending on your physical and emotional needs. Don't hesitate to ask, and ask early during your care.

Palliative care

Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. Palliative care is an approach to care that addresses the person as a whole, not just their disease. The goal is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to any related psychological, social, and spiritual problems. Patients may receive palliative care in the hospital, an outpatient clinic, a long-term care facility, or at home under the direction of a physician.

Palliative care can address a broad range of issues, integrating an individual's specific needs into care. A palliative care specialist will take the following issues into account for each patient:

- **Physical.** Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia.
- **Emotional and coping.** Palliative care specialists can provide resources to help patients and families deal with the emotions that come with a cancer diagnosis and cancer treatment. Depression, anxiety, and fear are only a few of the concerns that can be addressed through palliative care.
- **Spiritual.** With a cancer diagnosis, patients and families often look more deeply for meaning in their lives. Some find the disease brings them closer to their faith or spiritual beliefs, whereas others struggle to understand why cancer happened to them. An expert in palliative care can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation.
- **Caregiver needs.** Family members are an important part of cancer care. Like the patient, they have changing needs. It's common for family members to become overwhelmed by the extra responsibilities placed upon them. Many find it hard to care for a sick relative while trying to handle other obligations, such as work, household duties, and caring for other family members. Uncertainty about how to help their loved one with medical situations, inadequate social support, and emotions such as worry and fear can also add to caregiver stress. These challenges can compromise caregivers' own health. Palliative care specialists can help families and friends cope and give them the support they need.
- **Practical needs.** Palliative care specialists can also assist with financial and legal worries, insurance questions, and employment concerns. Discussing the goals of care is also an important component of palliative care. This includes talking about advance directives and facilitating communication among family members, caregivers, and members of the oncology care team.

Hospice care

Hospice is a special type of care in which medical, psychological, and spiritual support are given to patients and their loved ones when cancer therapies are no longer controlling the disease. Although both hospice and palliative care provide comfort and support for patients, palliative care is available throughout a patient's experience with cancer. A person's cancer treatment continues while one is receiving palliative care, but with hospice care, the focus has shifted to just relieving symptoms and providing support at the end of life.

Questions to ask your doctor about making the transition from cancer treatment to hospice care

1. How do I decide whether to continue, stop, or not start treatment?
2. When should I consider having hospice care?
3. How can I make sure I have the best quality of life possible—that I am comfortable and free of pain?
4. Can I have hospice care in my home, or do I have to go to a special facility?
5. How can I get help with financial and legal issues (for example, paying for hospice care or preparing a will or an advance directive)?
6. How can I get help with my spiritual needs?

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Talking about these questions may help you decide whether to continue, end, or not start active treatment. Tell your healthcare team exactly what you want to know, and how much you can take in. If possible, it's best to involve your loved ones in this process. It will help you understand what you need and what those close to you need.

Advance Directives

It's important to start talking about your wishes with the people who matter most to you. There may come a time when you can't tell your healthcare team what you need. Some people prefer to let their doctor or their family members make decisions for them. But often people with cancer feel better once they have made their desires known. (See **Advance Care Planning** on page 60.)



“You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, ‘I have lived through this...I can take the next thing that comes along.’ You must do the thing you think you cannot do.” -Eleanor Roosevelt

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