


# Paths to Survivorship™

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



*Paths to Survivorship* is produced by Bag It. In addition to the Bag It team we would like to attribute content in this publication to the organizations listed below. We are thankful for their generous contribution to provide helpful, accurate, and timely resources for those navigating cancer survivorship.



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# Paths to Survivorship

You are a **cancer survivor**—regardless of whether you were diagnosed today or decades ago. The National Coalition of Cancer Survivorship defines Survivorship as the process of living with, through, and beyond a cancer diagnosis.

Bag It compiled information from premier cancer organizations to create *Paths to Survivorship*, a tool to help cancer survivors and their loved ones to better understand and navigate the phases of survivorship.

Every cancer is different and every cancer survivor is different so we've included a lot of information in this book. Know that not all of it will apply to you. Check out the sections that you need now and read more later when another topic interests you. Feel free to mark up the pages. Bookmark what's especially helpful and something you want to read again. Visit [www.BagItCancer.org](http://www.BagItCancer.org) for more resources on every topic discussed and more.

It is our hope that by using *Paths to Survivorship*, you will feel more informed and empowered to be part of your care team, better able to express yourself to ensure your needs are met, and more in control to live your best life possible with cancer.



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# [1]

## Self-Advocacy as a Cancer Survivor

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Self-advocacy is the ability to communicate one's needs and to make informed decisions about the kinds of help and support one wants.



# What Is Self-Advocacy and How Does It Apply To Me?

Self-advocacy does not mean that you have to wave a banner, give speeches or take to the ramparts. In the personal context, it means that you arm yourself with the tools and skills necessary to feel comfortable about asserting yourself and communicating clearly about your cancer care needs. It ultimately means that you are taking responsibility and assuming some control of your life circumstances with cancer.

## Why is self-advocacy important?

By being a proactive, educated cancer consumer/advocate, you can impact the quality of your life and the healthcare you receive. Stated in another way, self-advocacy is a synonym for what some might otherwise call “control” or “empowerment.” Self-advocacy implies strength, both physical and mental. Self-advocacy requires participation in the decision-making process.

Given our tremendous access to resources for information and support today, a self-advocate need not go to a medical provider and say, “What would you do?” or “I’m in your hands,” or “Just cure me.” Commitment to shared responsibility with your medical team can contribute to the goal of physical, emotional, and mental health.

## How do I advocate for myself?

*Paths to Survivorship* and the accompanying contents in your **Bag It** bag guide you with suggestions and tips on how to be actively involved in your care from the moment of diagnosis through each phase of survivorship. Start with questions to ask your healthcare team and ways to work together with them.

Read the reliable information from reputable organizations on many cancer-related topics, and you will be better equipped to make sound decisions about your treatment and care. You will feel more in the driver’s seat and better able to cope. Read on to be informed and be empowered.

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

# Tips on How to Be Your Own Advocate

- Use your **Bag It** *My Companion Guidebook* to stay organized, track your own information, and as a handy source for reliable resources.
- Assemble and work closely with all the members of your healthcare team who have your best interests in mind. (see healthcare team definitions on page 4)
- Educate yourself about your specific cancer so you can make informed decisions about your treatment and care. (see Questions to ask your healthcare team on page 10)
- Visit only reliable websites for cancer information. (see Resources section of *My Companion Guidebook*)
- Thoroughly understand your health insurance policy.
- Request copies of all of your medical records and test results to store in *My Companion Guidebook*. You can refer back to them and provide as a back-up copy in case they get lost.
- Ask lots of questions – about your cancer diagnosis, treatment options, possible side effects, and available resources for yourself and your loved ones. (see questions to ask your healthcare team on pages 10 and 21)
- Bring someone with you to every appointment and let them know how they can help you.
- Use the *My Appointments Summary Log* found in *My Companion Guidebook* to write down your questions in advance of appointments. Make sure you fully understand the answers provided and take notes.
- Take an active role in managing your care. Consider getting a second opinion.
- Express fully and honestly what you need and want—to your healthcare team, caregivers, family members, and friends.
- Keep your healthcare team updated on any changes in your health. Fully and promptly report symptoms and side effects during and after treatment.
- When challenges arise, problem solve and negotiate to achieve your goals and ensure you have the best care and support you need.
- Ask others for help. Having a loved one or friend advocate on your behalf is a form of self-advocacy.



# [2]

## Diagnosis and Treatment

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### 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. You may have some or all of the following healthcare professionals caring for you at some point or throughout your cancer treatment and beyond.

#### **Cancer surgeon**

A doctor who performs procedures and surgeries to diagnose and treat cancer.

#### **Case manager**

Case managers are usually registered nurses 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 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.

#### **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.

### **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 work closely with doctors and the cancer team, and can prescribe medications and order tests.

### **Oncology social worker**

A professional trained to help people with cancer and their families 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 also 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 who has special training in preparing and dispensing (giving out) prescription drugs. Pharmacists have been taught how drugs work, how to use them, and their side effects.

## Radiation oncologist

A doctor who has special training in using radiation to treat cancer.

### *Helpful Tips!*

- Be sure to ask questions if you are unsure about a team member's role or if you would like a particular healthcare professional to be part of your team.
- Use the *My Appointments Summary Log* in Section 2 of *My Companion Guidebook* to jot down your questions for your healthcare team and the answers they provide.
- Smartphone and tablet users can download apps for Cancer.Net Mobile or Pocket Cancer Care Guide to build a list of questions for their doctor and record the answers.
- Don't forget to bring someone with you to your appointments, especially at the beginning.

# 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 him/her to say.
- **Ask questions and gather information.** Make sure you understand what was said and that you have the best information to make decisions.
- **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, consider changing medical 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.

See questions to ask about diagnosis and treatment on pages 10 and 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 survivor to survivor, 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 cancer survivors have curable disease while others have more advanced cancer, which may not be able to be completely removed. 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.

*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. Ensure you get the information you need to make informed decisions about your health. Your values and beliefs may impact your treatment choices as well. Treatment planning is also a good time to consider getting a second opinion.*



## Questions to ask your healthcare team about your diagnosis

Some of these questions may not apply to you or your cancer, but we hope the following 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 different types of 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 are the goals for treatment?
7. Who will be on my care team?
8. What is the best way to reach you for non-urgent questions or concerns?
9. Where can I find more information on my diagnosis and treatment? Where can I find local support resources?
10. Is participation in a clinical trial an option for me? (see Clinical Trials on page 17)

See **Questions to ask your healthcare team** about cancer treatments on page 21.

# Other Considerations at the Time of Diagnosis

## Genetic testing for cancer risk

Genetic testing helps estimate your chance of developing cancer in your lifetime. It does this by searching for specific changes in your genes, chromosomes, or proteins. These changes are called mutations. Genetic testing may help:

- Predict your risk of a particular disease.
- Find out if you have genes that may pass increased cancer risk to your children.
- Provide information to guide your health plan.

## Risk factors for a hereditary cancer

A hereditary cancer is any cancer caused by gene mutation. The following factors suggest a possible increased risk:

- Family history of cancer. Having 3 or more relatives on the same side of the family with the same or related forms of cancer.
- Cancer at an early age. Having 2 or more relatives diagnosed with cancer at an early age. This factor may differ depending on the type of cancer.
- Multiple cancers. Having 2 or more types of cancer occurring in the same relative.

*Genetic counseling is recommended before and after genetic testing. No genetic test can say whether you will develop cancer for sure. But it can tell you if you have a higher risk than most people. Genetic testing is a complex decision best made in collaboration. Engage your family, doctor and genetic counselor in the process.*

## 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.

## Advanced cancer

Should you learn that you have advanced cancer, see section 6, Living with Chronic and Advanced Cancer on page 69 for treatment options and questions to ask your doctor.

## Helpful Tips!

- Before appointments, review the hints on communicating with your healthcare team and the lists of questions found in this section.
- Bring someone with you to your appointments.
- Use the *My Appointments Summary Log* found in section 2 of *My Companion Guidebook* to write down your questions and answers.
- Refer to the Resources section in *My Companion Guidebook* for reliable websites with more information on your cancer type, treatments, and questions to ask your doctor.
- The National Comprehensive Cancer Network offers The NCCN Guidelines for Patients® with specific information about many types of cancer.

Visit: [www.nccn.org/patients](http://www.nccn.org/patients)



# 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 solid 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 can be given in several ways; the most common method is intravenous (IV) 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. For example, a drug may be given daily for 4 weeks followed by a 2-week break. 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.

***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.***



## *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. Most chemotherapy is given intermittently (for example, once a week) with time in between doses for recovery. Treatment periods are called cycles (usually 3 or 4 weeks). Several of these cycles complete a course of chemotherapy, which generally lasts 3 months or longer. A treatment session may take minutes, hours, or, in some cases, days. 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.

## **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. Your first radiation therapy session is called a simulation and does not involve an actual treatment.

During this visit, the medical team will position your body and adjust the radiation beam to target the tumor, the location of which may be marked on the skin with a very small, dot-like temporary or permanent tattoo. In addition, special blocks, shields, or immobilizers may be used to position your body correctly. Once treatment begins, often a few days after the simulation, your radiation oncologist will evaluate your progress weekly 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.

### *What are the types of immunotherapy?*

There are several types, including monoclonal antibodies, cancer vaccines, oncolytic virus therapy, T-cell therapy, and non-specific immunotherapies.

***See Side Effects During Treatment starting on page 33.***

## Hormone therapy

Hormone therapy is a treatment that slows or stops the growth of breast and prostate cancers that use hormones to grow.

## 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 genetic 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. Targeted therapies differ from standard chemotherapy. Cancer vaccines and gene therapy are sometimes considered targeted therapies because they interfere with the growth of specific cancer cells. For some types of cancer, most patients with that cancer will have an appropriate target for a particular targeted therapy and, thus, will be candidates to be treated with that therapy.





## Clinical trials

### *What is a clinical trial?*

A clinical trial is a research study that involves volunteers. These types of studies help doctors find better treatments for cancer and other diseases. The U.S. government and other governments have strict rules to protect people in a clinical trial. All clinical trial doctors and staff must follow these rules.

### *Does being in a clinical trial mean there is no cure?*

Some clinical trials need volunteers who have not tried certain treatments yet. Well-known treatments are still available, but the clinical trial might also help. So you might want to try the clinical trial treatment first. Some clinical trials are for people whose regular treatments did not work. There is a chance that the treatment being researched might help. Or it might not. It is important to talk with your healthcare team about the possible benefits and risks for you. The results of the clinical trial will give doctors valuable information on treating this type of cancer. It can help other patients in the future.

## *What do cancer clinical trials study?*

Many cancer clinical trials are looking for a cure. This means safer, more effective ways of destroying cancer cells and keeping them from coming back. These ways can include:

- A completely new drug, such as chemotherapy, targeted therapy, or immunotherapy.
- A new way of giving radiation therapy or doing surgery.
- A new combination of different treatments. For example, using a new drug plus surgery or a new combination of drugs.

In other clinical trials, doctors test different things. These could include:

- A way to reduce side effects of treatment. For example, developing a new drug that helps people feel less nauseous after chemotherapy.
- Treatment for health problems that may occur after cancer or cancer treatment.
- A new way to find cancer or prevent it. For example, changes in eating habits or a new cancer screening test.

You might want to be in a clinical trial for the following reasons:

- To try a new treatment that is not available to everyone.
- Because the treatment offered in the clinical trial is a good choice for you.
- To prevent or manage side effects.
- To help improve cancer care for everyone.
- To help doctors get better at looking for cancer and finding it early.

If you or your loved one has cancer, talk with your healthcare team about clinical trials. Every clinical trial is different. Some clinical trials need volunteers who have tried all the regular treatments. Others need volunteers who have tried some treatments, but not all.

## *Learn More About Clinical Trials*

<https://www.clinicaltrials.gov>

<https://www.cancer.gov/about-cancer/treatment/clinical-trials/search>

<https://www.cisr.org/slide-item/search-clinical-trials/>



# 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. These options may include:

- Surgery.
- Radiation therapy.
- Chemotherapy.
- Hormone therapy.
- Targeted therapy.
- Immunotherapy.
- Active surveillance, also called watchful waiting.
- Palliative care.
- Participating in a clinical trial.

## 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 not being able to have children. You have more options to keep your fertility if you address this concern before treatment, instead of waiting until after treatment.

## 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. First check with your insurance company to find out if your policy covers a specific doctor or healthcare system.

## 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.

## Consult guidelines or other decision-making tools

The American Society of Clinical Oncology (ASCO) and other cancer organizations publish guidelines and treatment decision-making tools. These tools help doctors and patients understand various treatment options. Learn more about treatment recommendations for the specific type of cancer that you have. Talk with your healthcare team to find out more details about treatment recommendations.

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

# Precautions and Adherence to Treatments

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.

- Avoid contact with ill persons.
- Wash your hands frequently.
- Eat fresh food, prepared in a reputable establishment or from home. Wash or cook vegetables and/or fruits before consuming.

## 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:

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

## Radiation therapy

If you are undergoing radiation:

- 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 your treatment includes internal radiation treatment such as implanted radiation seeds (brachytherapy) or taking a radioactive pill, your care providers will give you more specific instructions on precautions for you and your caregivers to follow at home.
- If you develop a rash, ask your doctor or nurse for recommendations regarding skin products or creams to help.

## Pregnancy

Many cancer treatments are harmful to a developing fetus. If you are taking anti-



cancer therapy, ask your healthcare team if it is safe for you to have sex, become pregnant (females) or impregnate your partner (males). Additionally, some form 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 select a birth control method that works for you and your partner.

### When to call your doctor right away

If you have the following symptoms or anything listed on the printed information given to you by your healthcare team:

- A fever of 100.5°F or higher, taken by mouth.
- Chills, shaking (rigors) and/or sweats.
- Bleeding.
- Burning with urination.
- Pain or redness at the IV site where the chemo was given.
- Uncontrolled nausea, vomiting, or diarrhea.

### The importance of following your treatment plan

Your healthcare team has your best interests in mind when they give you medical advice and prescribe medication and other cancer treatments. Stick with your care plan and keep the conversation going when you have questions or concerns, especially if you are experiencing side effects. In many cases these can be managed and relieved with a quick phone call between office visits and your treatment can continue. Be sure to fill all the prescriptions you receive. Make sure you understand what medications you are taking, why, when, and how they are to be taken. Medications should be taken at the right time and in the correct dose for the full duration prescribed—even if you feel better. 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.

## Medication Tips and Tricks

- Use the customizable log in Section 2 of *My Companion Guidebook* to keep track of medications you take.
- Create a reminder system—use a calendar, an app, phone or other alarm.
- Enlist the help of your caregivers or friends to remind you.
- Incorporate taking your medications into your daily routine.
- If you go on a trip, be sure to pack your medications in your carry on bag, never your checked luggage.
- Financial assistance may be available to help if you can't pay for your medications.



# 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 page 75 for additional information)



## 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 page 33 for more information on complementary therapies)

## Natural does not mean safe

CAM therapies include a wide variety of botanicals and nutritional products, such as dietary supplements, herbal supplements, and vitamins. Many of these “natural” products are considered to be safe because they are present in, or produced by, nature. However, that is not true in all cases. In addition, some may affect how well other medicines work in your body. For example, the herb St. John’s wort, which some people use for depression, may cause certain anticancer drugs not to work as well as they should.

## Supplements

Herbal supplements may be harmful when taken by themselves, with other substances, or in large doses. For example, some studies have shown that kava kava, an herb that has been used to help with stress and anxiety, may cause liver damage. Vitamins can also have unwanted effects in your body. For example, some studies show that high doses of vitamins, even vitamin C, may affect how chemotherapy and radiation work. Too much of any vitamin is not safe, even in a healthy person. Tell your doctor if you’re taking any dietary supplements, no matter how safe you think they are. This is very important. Even though there may be ads or claims that something has been used for years, they do not prove that it’s safe or effective. Supplements do not have to be approved by the federal government before being sold to the public. Also, a prescription is not needed to buy them. Therefore, it’s up to consumers to decide what is best for them.



# 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, 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 you happy in the past. Explore this place or activity. Notice how calm you feel.
- If you ever feel out of breath, take a deep breath, and continue the slow breathing.

Learn more at <https://www.cancer.gov/about-cancer/coping/feelings/relaxation>

# [3]

## Coping with Cancer

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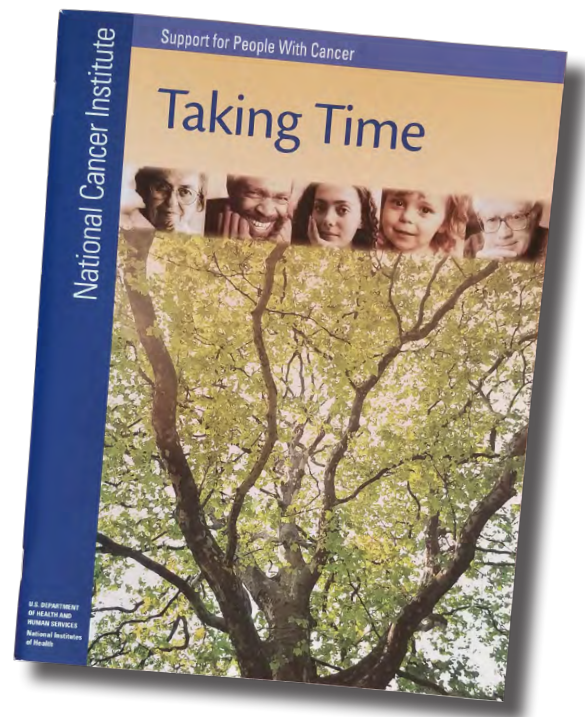
### Your Emotions

A cancer diagnosis usually brings with it a flood of emotions—for you and everyone around you. A wide range of feelings is normal and they can change quickly. They can be intense or numbing. They can be different for each person. But they are real, to be sure.

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 the difficulties you may experience along the way including:

- Changes in your roles and relationships, with yourself, spouse/partner, family members, and close friends.
- Guidance on talking with young and adult children.
- Tips on where and how to build your team for support and help you might need today or in the future. You do not have to handle this challenge on your own.

Use what is helpful in the booklet now or look at it later when you are ready. Share the booklet with those around you as you see fit. Additional information is available on our website: [www.BagItCancer.org/resources](http://www.BagItCancer.org/resources)




*Fear of the unknown is often a source of distress during diagnosis and early treatment phases.*



## Distress

Patients living with cancer feel many different emotions, including anxiety and distress. Anxiety is fear, dread, and uneasiness caused by stress. Distress is emotional, mental, social, or spiritual suffering. Patients who are distressed may have a range of feelings from vulnerability and sadness to depression, anxiety, panic, and isolation.

Patients may have feelings of anxiety and distress while being screened for a cancer, waiting for the results of tests, receiving a cancer diagnosis, being treated for cancer, or worrying that cancer will recur (come back). Anxiety and distress may affect a patient's ability to cope with a cancer diagnosis or treatment. It may cause patients to miss check-ups or delay treatment. Anxiety may increase pain, affect sleep, and cause nausea and vomiting. Even mild anxiety can affect the quality of life for cancer patients and their families and may need to be treated.



National  
Comprehensive  
Cancer  
Network®

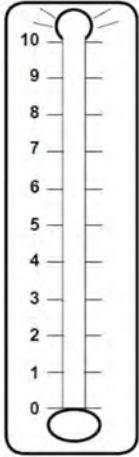
**NCCN Guidelines Version 2.2018**  
**Distress Management**

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**NCCN DISTRESS THERMOMETER**

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**  
Please indicate if any of the following has been a problem for you in the past week including today.  
Be sure to check YES or NO for each.

YES NO <u>Practical Problems</u>	YES NO <u>Physical Problems</u>
<input type="checkbox"/> <input type="checkbox"/> Child care	<input type="checkbox"/> <input type="checkbox"/> Appearance
<input type="checkbox"/> <input type="checkbox"/> Housing	<input type="checkbox"/> <input type="checkbox"/> Bathing/dressing
<input type="checkbox"/> <input type="checkbox"/> Insurance/financial	<input type="checkbox"/> <input type="checkbox"/> Breathing
<input type="checkbox"/> <input type="checkbox"/> Transportation	<input type="checkbox"/> <input type="checkbox"/> Changes in urination
<input type="checkbox"/> <input type="checkbox"/> Work/school	<input type="checkbox"/> <input type="checkbox"/> Constipation
<input type="checkbox"/> <input type="checkbox"/> Treatment decisions	<input type="checkbox"/> <input type="checkbox"/> Diarrhea
	<input type="checkbox"/> <input type="checkbox"/> Eating
	<input type="checkbox"/> <input type="checkbox"/> Fatigue
<input type="checkbox"/> <input type="checkbox"/> <u>Family Problems</u>	<input type="checkbox"/> <input type="checkbox"/> Feeling swollen
<input type="checkbox"/> <input type="checkbox"/> Dealing with children	<input type="checkbox"/> <input type="checkbox"/> Fevers
<input type="checkbox"/> <input type="checkbox"/> Dealing with partner	<input type="checkbox"/> <input type="checkbox"/> Getting around
<input type="checkbox"/> <input type="checkbox"/> Ability to have children	<input type="checkbox"/> <input type="checkbox"/> Indigestion
<input type="checkbox"/> <input type="checkbox"/> Family health issues	<input type="checkbox"/> <input type="checkbox"/> Memory/concentration
	<input type="checkbox"/> <input type="checkbox"/> Mouth sores
<input type="checkbox"/> <input type="checkbox"/> <u>Emotional Problems</u>	<input type="checkbox"/> <input type="checkbox"/> Nausea
<input type="checkbox"/> <input type="checkbox"/> Depression	<input type="checkbox"/> <input type="checkbox"/> Nose dry/congested
<input type="checkbox"/> <input type="checkbox"/> Fears	<input type="checkbox"/> <input type="checkbox"/> Pain
<input type="checkbox"/> <input type="checkbox"/> Nervousness	<input type="checkbox"/> <input type="checkbox"/> Sexual
<input type="checkbox"/> <input type="checkbox"/> Sadness	<input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy
<input type="checkbox"/> <input type="checkbox"/> Worry	<input type="checkbox"/> <input type="checkbox"/> Sleep
<input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities	<input type="checkbox"/> <input type="checkbox"/> Substance use
	<input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet
<input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u>	
Other Problems: _____	

Most people with cancer have some degree of distress at some point. A member of your healthcare team may periodically ask you to complete a distress screening. They might ask you a few questions or give you a paper survey that asks you to rate the level of distress you are feeling and indicate problems you have been experiencing recently (see example above). If you have a high level of distress, your healthcare team will discuss your concerns and offer other services and/or other resources to help you. Speak candidly. Let them know what you are coping with to ensure that you get the care and support you need. (see palliative care on page 24)

# 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.

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.

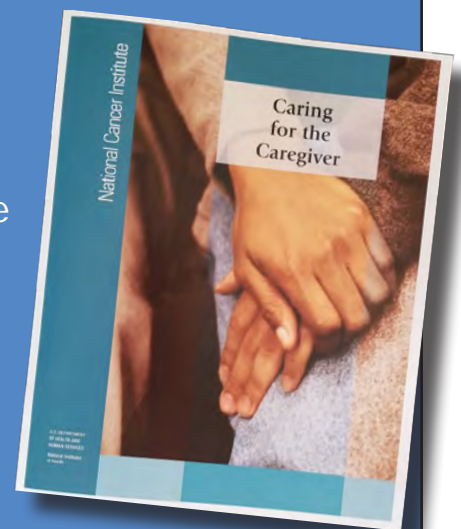
As any person with cancer knows, a cancer diagnosis also affects family members and friends. Sometimes, the complex feelings and lifestyle changes caused by cancer and its treatment become as overwhelming for others in your life as they are for you. Understanding the potential changes in the way you 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 help and 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 [www.BagItCancer.org/resources](http://www.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.

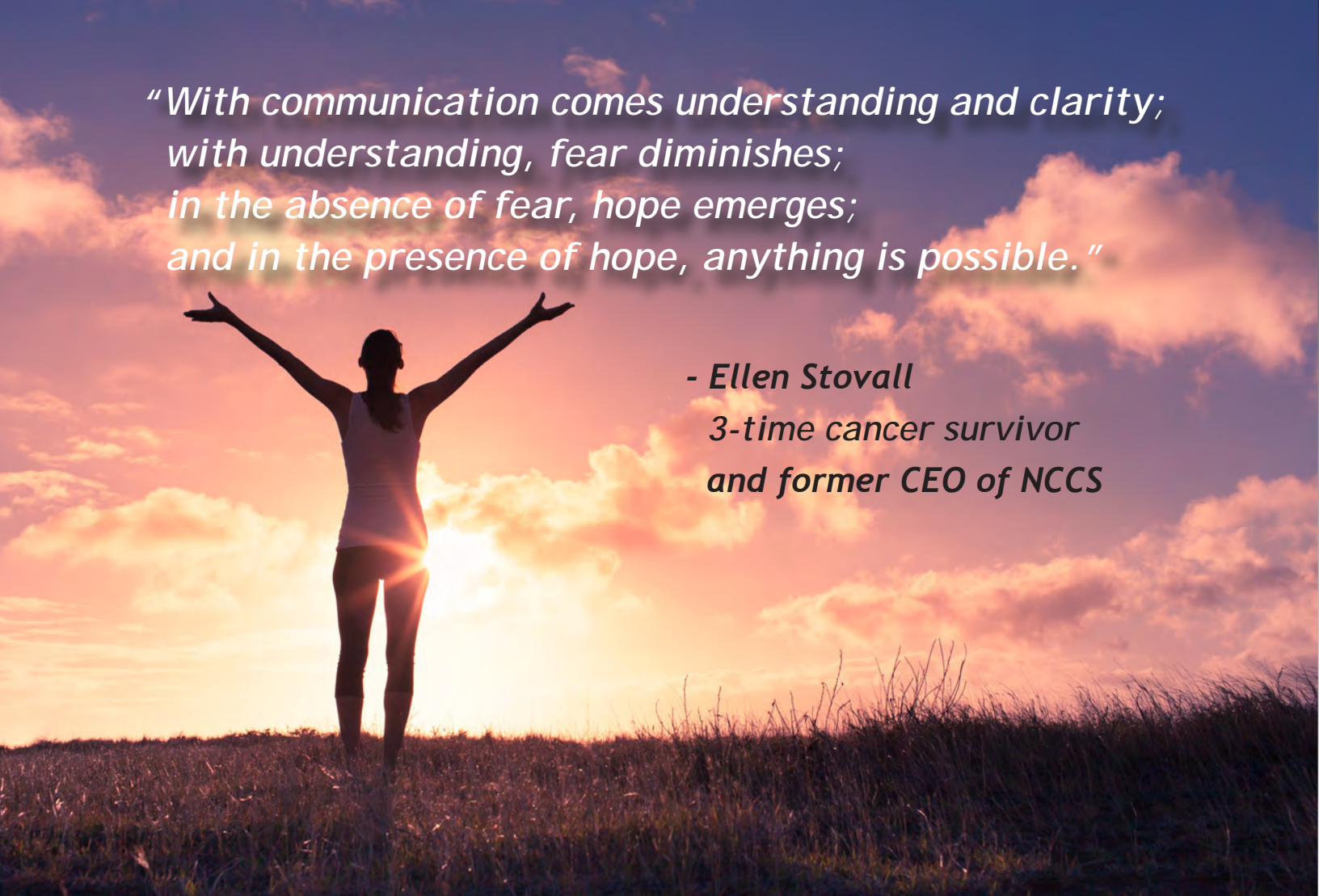
## Tips for talking with your children

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 [www.BagItCancer.org/resources](http://www.BagItCancer.org/resources).*



A person stands in a field of tall grass, their back to the camera with arms raised in a 'V' shape. The sun is low on the horizon, creating a bright glow and long shadows. The sky is filled with soft, orange-tinted clouds.

*"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. For example, they might question their relationship with God.

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.
- 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 During Treatment

Your cancer treatment(s) can last weeks, months or perhaps for the rest of your life. The treatments may affect how you physically look and feel. Some of your cancer treatments may cause you to experience some side effects, but know that side effects vary from person to person, even among those receiving the same treatment. Your healthcare team will talk to you about the possible side effects you might experience and how they can be managed. Ask lots of questions of your healthcare team about side effects before and during your treatment, and let them know about any new symptoms you experience.

Some side effects are limited to the duration of treatment; once your treatment ends, the side effects go away. Other side effects (also called long-term side effects) can last for months or years after treatment is completed. Late effects are certain side effects of treatment that are not apparent until after the treatment is completed. (see late and long-term side effects on page 66)

## Supportive care

Palliative care and some complementary therapies offer ways to prevent, manage, and/or relieve cancer-related discomfort. It can improve your quality of life physically and emotionally. Ask your healthcare team about these types of support.

Many cancer survivors find relief from complementary therapies. While it does not work for everyone, it may help you manage stress, nausea, pain, or other symptoms or side effects. Be sure to talk to your doctor before you try anything new. Caregivers and family friends could also benefit from some therapies for stress and anxiety. Here are a few complementary therapies that can ease common side effects and concerns of cancer survivors.

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 a focus on the breath 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

Ask your healthcare team which therapies and/or treatments would be appropriate for your stage in treatment and phase of survivorship, as some are not recommended at all times. Also ask where you can obtain the services from qualified providers and facilities. 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.

## Common side effects

The *Heal Well* booklet in your **Bag It** bag offers tips on how to manage eating concerns during treatment that can cause:

- Changes in appetite.
- Nausea and vomiting.
- Bowel changes: diarrhea and constipation.
- Changes in taste and smell.
- Sore mouth or throat.
- Unwanted weight gain or weight loss.

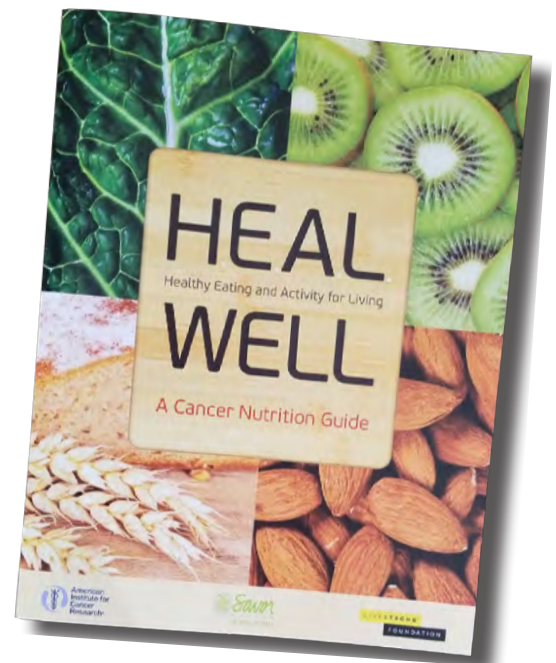
*Heal Well* also gives suggestions on how physical activity can help you to manage cancer treatment side effects and how to eat well during treatment and beyond.

Visit [www.BagItCancer.org/resources](http://www.BagItCancer.org/resources) for more information on eating hints during treatment.

## Cancer-related fatigue

### *What is cancer-related fatigue?*

Cancer-related fatigue is a persistent feeling of physical, emotional, or mental tiredness or exhaustion related to cancer and/or its treatment. Unlike other types of fatigue, the feeling does not go away with 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 aim for or build up to 150 minutes



of moderate activity per week, such as fast walking, cycling, or swimming, plus 2 to 3 strength training sessions per week. 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 patients find that acupuncture and mindfulness-based approaches such as yoga may help as well. (see page 33 for more information about complementary and integrative therapies)

## Pain

Many people with cancer experience pain, which can 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.

### *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.

*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.*

## *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 page 33 for more information on complementary therapies)

*Use the customizable log in Section 2 of My Companion Guidebook to keep track of side effects and symptoms you are experiencing. Be sure to accurately report them to your health care team. Note frequency, duration and intensity.*

## 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:	Lymphedema that is not controlled may cause:
<ul style="list-style-type: none"> <li>• Swelling and a heavy or achy feeling in your arms or legs that may spread to your fingers and toes.</li> <li>• A dent when you press on the swollen area.</li> <li>• Swelling that is soft to the touch and is usually not painful at first.</li> </ul>	<ul style="list-style-type: none"> <li>• Swelling and a tight uncomfortable feeling on your face, neck, or under your chin.</li> <li>• Difficulty moving your head or neck.</li> </ul>	<ul style="list-style-type: none"> <li>• More swelling, weakness, and difficulty moving your arm or leg.</li> <li>• Itchy, red, warm skin, and sometimes a rash.</li> <li>• Wounds that don't heal, and an increased risk of skin infections that may cause pain, redness, and swelling.</li> <li>• Thickening or hardening of the skin.</li> <li>• Tight feeling in the skin; pressing on the swollen area does not leave a dent.</li> <li>• Hair loss.</li> </ul>

### *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. All white blood cells help the body fight infection. Neutrophils fight infection by destroying harmful bacteria and fungi (yeast) that invade the body. Some level of neutropenia takes place in about half of people with cancer who are receiving chemotherapy. It is a common side effect in people with leukemia. If you have neutropenia, practice good personal hygiene to lower your risk of infection. This includes washing your hands regularly. 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.

### *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.



## 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 here, 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:

- Tingling, numbness, or a pins-and-needles feeling in your feet and hands that may spread to your legs and arms.
- 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:

- Weak or achy muscles. You may lose your balance or trip easily. It may also be difficult to button shirts or open jars.

## Helpful Tips!

Talk with your healthcare team right away if you have any of these signs of infection:

- A fever, which is a temperature of 100.5°F or higher.
- Chills or sweating.
- Sore throat, sores in the mouth, or a toothache.
- Abdominal pain.
- Pain near the anus.
- Pain or burning when urinating, or urinating often.
- Diarrhea or sores around the anus.
- A cough or shortness of breath.
- Any redness, swelling, or pain (especially around a cut, wound, or catheter).
- Unusual vaginal discharge or itching.

- Muscles that twitch and cramp or muscle wasting (if you don't use your muscles regularly).
- 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:

- Digestive changes such as constipation or diarrhea.
- Dizzy or faint feeling, due to low blood pressure.
- Sexual problems; men may be unable to get an erection and women may not reach orgasm.
- Sweating problems (either too much or too little sweating).
- 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. If chemotherapy is the cause, the doctor may treat it with erythropoiesis-stimulating agents, which tell the bone marrow to make more red blood cells. However, these drugs can be associated with other health risks.



## Attention, thinking, or memory problems (also known as chemo brain)

### *What is chemobrain?*

Chemobrain is a common term used to describe the cognitive problems that cancer survivors often face during and after chemotherapy. People sometimes use this term to describe cognitive symptoms that may arise from other types of cancer treatments, such as radiation therapy or hormone therapy. Cognitive problems occur when a person has trouble processing information. This includes mental tasks related to attention span, thinking, and short-term memory. These problems vary in severity and often make it hard to complete daily tasks. Lots of people with cancer have cognitive problems during chemotherapy. 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.

### *What causes chemobrain?*

Although the cause of chemobrain is not well understood, the most likely cause is the effect of chemotherapy on the brain. Hormonal changes are also likely to play a role.

## *What are the symptoms of chemobrain?*

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.

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.

## *How is chemobrain managed and treated?*

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 learning a new hobby.

*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. Remember, the symptoms of chemobrain gradually improve in the large majority of cancer survivors after chemotherapy ends.*



## 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, also called alopecia, may be a side effect of chemotherapy, targeted therapy, radiation therapy, or bone marrow/stem cell transplants. These treatments can cause hair loss by harming the cells that help hair grow. Hair loss may occur throughout the body, including the head, face, arms, legs, underarms, and pubic area. Hair may fall out entirely, slowly, or in sections. A person's hair may also simply become thin, sometimes unnoticeably, and it may become duller or dryer. Hair loss related to cancer treatment is usually temporary. Most of the time, hair will grow back. Rarely, it may remain thin.

Hair does not usually fall out right away after you start chemotherapy. Most of the time, it begins to fall out after several weeks or cycles of treatment. Hair loss tends to increase 1 to 2 months into treatment. The amount of hair loss varies from person to person. Even people taking the same drugs for the same cancer will have a different amount of hair loss. How much hair you lose depends on the drug and the dose. It also depends on whether you receive the drug as a pill, into a vein, or on the skin. Hair starts to regrow about 1 to 3 months after chemotherapy ends. It often takes about 6 to 12 months for your hair to regrow completely. When new hair regrows, its texture may feel different than before. You may notice that your hair grows back thinner or coarser. The color of regrown hair may also be different than before. Hair will usually go back to normal after several years.



## 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.
- Biological therapy may cause itching (pruritus).
- Targeted therapy may cause a 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.

# **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.

## **Symptoms of infection requiring immediate care**

People experiencing these symptoms may need emergency care. Call your healthcare team right away if you have 1 or more of the signs listed below. If your symptoms cannot be assessed right away, you may need to go to the emergency room.

- Fever that is 100.5° F (38° C) or higher.
- Shaking chills.
- Chest pain or shortness of breath.
- Confusion.
- Severe headache with a stiff neck.
- Bloody or cloudy urine.



# Practical Matters

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



# Workplace Issues

## Working during treatment

Many people are able to continue working during their treatments and being proactive can make all the difference. The keys are good communication with your healthcare team, knowing up front what the expected side effects will be, and developing a plan with your doctor.

- Let your doctor know if work is a priority for you throughout treatment.
- Describe your work hours and what your job entails to your doctor. It's also important to include any unique circumstances that may be difficult for you throughout treatment.
- Ask your doctor what to expect during treatment and how treatment can affect your job performance.
- Be prepared for treatment side effects and ask your doctor how you can best manage side effects during work hours.
- Talk to your doctor about the best time to schedule treatment or take any medications to minimize side effects during your work hours.
- Ask about treatment options that might make it easier for you to continue working, like oral chemotherapies.

## Know your rights

Americans with Disabilities Act (ADA) requires that organizations with 15 or more employees comply with ADA guidelines. The ADA recommends that any accommodation that you need does not cause "undue hardship" to your employer. The following are possible accommodations options under the ADA:

- Flexible work hours to meet treatment schedules and doctor appointments are the most frequent workplace accommodation required by people living with cancer. If you require flextime, it is important to disclose your cancer diagnosis to your supervisor or Human Resources to be protected under the ADA. If no reason is given for frequent requests of flextime, you could risk jeopardizing your job security.
- Periodic breaks or a private area to rest or to take medication.
- Approval to work at home.
- Modification of office temperature.
- Permission to use work telephone to call doctors where the employer's usual practice is to prohibit personal calls.
- Reallocation or redistribution of marginal tasks to another employee.

Family Medical Leave Act (FMLA) can cover some time off during treatment. Under FMLA, an employee can take up to 12 weeks of unpaid leave per 12-month time period. To be eligible for FMLA benefits, an employee must: work for an employer (one who offers FMLA) where at least 50 employees are employed within 75 miles; have worked for the employer for a total of 12 months; and have worked at least 1,250 hours over the previous 12 months.

*FMLA has a provision for qualifying working family members to take FMLA leave in order to care for their ill family member (spouse, child, or parent).*

*For more information, visit the ADA website at [www.ada.gov](http://www.ada.gov) and the FMLA website at <https://www.dol.gov/whd/fmla/>*

## Obtaining employment

Under the ADA laws, you have the following rights:

- An employer cannot ask if a job applicant has or had cancer or about his/her treatment related to cancer prior to making a job offer.
- An applicant does not have to tell an employer that she/he has or had cancer before accepting a job offer.
- An employer cannot ask any follow-up questions if an applicant voluntarily tells the employer that he/she has or had cancer.

## Going back to work

For many people, returning to a full-time work schedule is a sign both to themselves and the world that they are getting back to “normal.” Working can provide opportunities to reconnect with colleagues and friends, focus on something other than cancer, get involved in interesting and challenging projects, and start settling back into a regular routine and lifestyle. However, transitioning back into the workforce may feel overwhelming at times. Every survivor’s work situation is different.

## Discrimination in the workplace

The Equal Employment Opportunity Commission (EEOC) is a federal agency that enforces the provisions of the ADA and FMLA and assists citizens who feel they have been discriminated against in the workplace. If you feel you are being treated unfairly, contact the EEOC, visit [www.eeoc.gov](http://www.eeoc.gov).

## Planning your return

For survivors who cut back on their hours or stopped working, the first step is to talk with your doctor or clinician about whether you are ready to return to work. The timing depends on the type of cancer and treatment you had and the type of



job you perform. If your job is stressful or physically demanding, you may need to wait longer before returning to work. Ongoing treatment or side effects, such as fatigue, may also cause delays. Once you know it's okay to return to work, a good next step is to set up a telephone or in-person meeting with your Human Resources department to discuss transition plans. Ask whether your employer has a formal "return-to-work" or disability management program. You may also want to discuss the possibility of flexible work arrangements, such as part-time hours, partial or full-time telecommuting, job sharing, reassignment to another position, leave time for doctor visits, or periodic work breaks to take medications and contact members of your healthcare team. These are all considered reasonable accommodations under the Americans with Disabilities Act (ADA).

Before granting a reasonable accommodation, your employer may request documentation that verifies your limitations, such as fatigue, chronic pain, and cognitive difficulties, which are classified as disabilities under the ADA. However, employers are not allowed to ask for your medical records. An employer may deny a request if the accommodation would cause an "undue hardship," such as being too difficult or expensive to implement. However, an employer is required to determine if there is an easier or less costly accommodation that can be made to meet your needs. Other things to consider to make your transition back to work smoother include:

- Planning to take small breaks throughout the day to help maintain your energy level.
- Using lists and reminders or setting meeting and task alarms on your office e-mail system.
- Scheduling frequent meetings with your manager to talk about the transition and make any necessary changes or adjustment.

## Talking with coworkers

It's your decision when and how to tell coworkers about your cancer experience, if you even decide to talk about it at all. However, if you have been absent for a while or your physical appearance has changed, some of your coworkers may have questions. It is important to decide what you want to tell people in advance and how you plan to do it. You may want to have private conversations with a few close coworkers. Or you may find it easier to send an e-mail or make an announcement at a staff meeting. Consider your work culture, what feels right to you, and your need for privacy versus your need for accommodations and support.

You can also ask your manager, a close coworker, or a human resources professional to help you decide if, when, and how to tell others about your cancer. It always helps to keep your explanation simple and let people know how your return to work will affect them.



# Financial Issues

## Health insurance

If you have health insurance, it should cover many of the costs of cancer care. To obtain all the benefits you're entitled to, it's important to understand how your health insurance policy works. Review your policy to find out what it covers and what you need to do to ensure coverage for your cancer treatment. Ask your insurance company if they can assign you a case manager to help you and answer your questions. You have the right to appeal if your health insurance company denies coverage for any aspect of your cancer care. Find out from your insurance company what you need to do to appeal a denial of coverage. If your appeal is denied, you may be able to get help from your state's insurance department.



*You may have a short- or long-term disability insurance policy that you purchased yourself or that is provided by your employer. It may cover some or all of your wages.*

## Managing your finances

The costs of cancer care can be high. Even people with reliable health insurance can be left with bills that quickly add up. Often, survivors have already lost income because they weren't able to work as much or at all during treatment, making it difficult to pay for both medical and household expenses. This financial stress may increase if you are unable to return to work after finishing treatment. Here are a few things to consider as you cope with the financial impact of cancer:

- **Investigate other sources of income if you are unable to return to work.** If a disability or other long-term side effect of cancer treatment has made it impossible for you to return to work, there are a number of potential sources of income to consider, including long-term disability insurance, life insurance policies, and retirement plans. Some cancer survivors apply for Social Security Disability Insurance or Supplemental Security Income. Learn more about these federal programs, including eligibility requirements: [www.ssa.gov/disability](http://www.ssa.gov/disability).
- **Organize bills and rank them in order of priority.** As you open your bills, organize them into categories such as medical bills, household bills, credit card statements, taxes, etc. Then figure out how much money you have in your budget to put toward payments. Your rent or mortgage, utilities, taxes, and medical expenses should be at the top of your bill-paying list.
- **Ask if the insurance payment can be considered “payment in full.”** If you are unable to pay for tests, procedures, and other treatments that were not completely covered by your insurance plan, making this request to the hospital, cancer center, or doctor's office is often more successful than people expect. Some hospitals have funds to offset medical services that aren't fully covered by insurance.
- **Talk to your creditors.** Usually if you call and explain your situation, your creditors or a credit counseling service will work with you to create a payment plan. Most companies would prefer receiving small payments, even \$10 a month, than nothing at all. Give the person you talk to a telephone number and the hours that you can be reached if there are any problems. Also ask them to communicate with you in writing.
- **Ask for help.** If you can't face the stack of bills that has collected, ask a trusted friend or family member to help you organize them and plan your budget. You can also talk with an oncology social worker or patient navigator about your financial concerns. They can help connect you with financial assistance programs and other sources of financial aid.
- **Contact an organization that offers help for cancer survivors facing financial challenges.** There are many national and local organizations that offer financial information, advice, and support for cancer survivors. Contact them directly to learn more about specific programs and services, including eligibility criteria.

# Financial Assistance

Help with cancer costs can come from many sources. A social worker or financial counselor may be able to help you find out what assistance you may qualify for and apply for it.

## Government programs

The federal government offers several programs that provide assistance with medical and living expenses. Many of these programs (including Medicare, Medicaid and Social Security) are designed to help people who are disabled or elderly or have low incomes. Many state governments also have programs to assist qualified state residents with medical and living expenses. Most government programs take time to process your application, so submit all paperwork as soon as possible.

## Public and nonprofit hospitals

Hospitals operated by state or local government and some nonprofit hospitals may provide a safety net for anyone who needs care, regardless of ability to pay. A social worker or your local health department may be able to help you find out what kind of “charity care” or “indigent care” programs are available in your community.

## Co-pay relief programs

Many organizations offer financial assistance to people with cancer who cannot afford to pay co-payments for pharmaceutical drugs. These organizations may also offer assistance with other expenses such as insurance premiums, deductibles and other out-of-pocket costs. Each organization offers different kinds of assistance and has its own eligibility rules. It is best to contact each organization to find out what is available.

## Patient assistance programs

Most pharmaceutical companies have patient assistance programs that may provide support for reimbursement issues, referrals to co-pay relief programs and help with applications for assistance. Many companies also offer medications at little or no cost to patients who qualify for assistance. Your healthcare team may be able to help you locate patient assistance programs for your medications.

***Visit our website for more information  
on patient assistance programs.  
[www.BagItCancer.org/resources](http://www.BagItCancer.org/resources)***



## Assistance from voluntary organizations

Nonprofit organizations may offer assistance with practical needs such as child care, household help and transportation. Each organization offers different kinds of assistance and may have its own eligibility rules. It is best to contact each organization to find out what is available. Fundraising may be an option to help pay for your cancer care. Make sure that raising funds will not disqualify you for benefits such as Medicaid or Social Security. Consult an organization that has experience raising funds for medical treatment. If you want the funds you raise to be tax-deductible for the donors, you will need to work with a tax-exempt organization. Be sure to follow Internal Revenue Service ([www.irs.gov](http://www.irs.gov)) guidelines for using tax-exempt donations.

## Personal financial planning

Consider seeking advice on your financial situation from a professional. An accountant may be able to help you save money on your income taxes. For example, you may qualify for tax credits that will reduce your taxes. If you have a lot of out-of-pocket medical expenses, you may be able to reduce your taxes by deducting some of those expenses from your income. A financial planner may be able to help you take control of your finances and plan for your financial future. Look for free or low-cost financial planning talks sponsored by organizations such as AARP ([www.aarp.org](http://www.aarp.org)) or by investment management companies.

# Life Planning

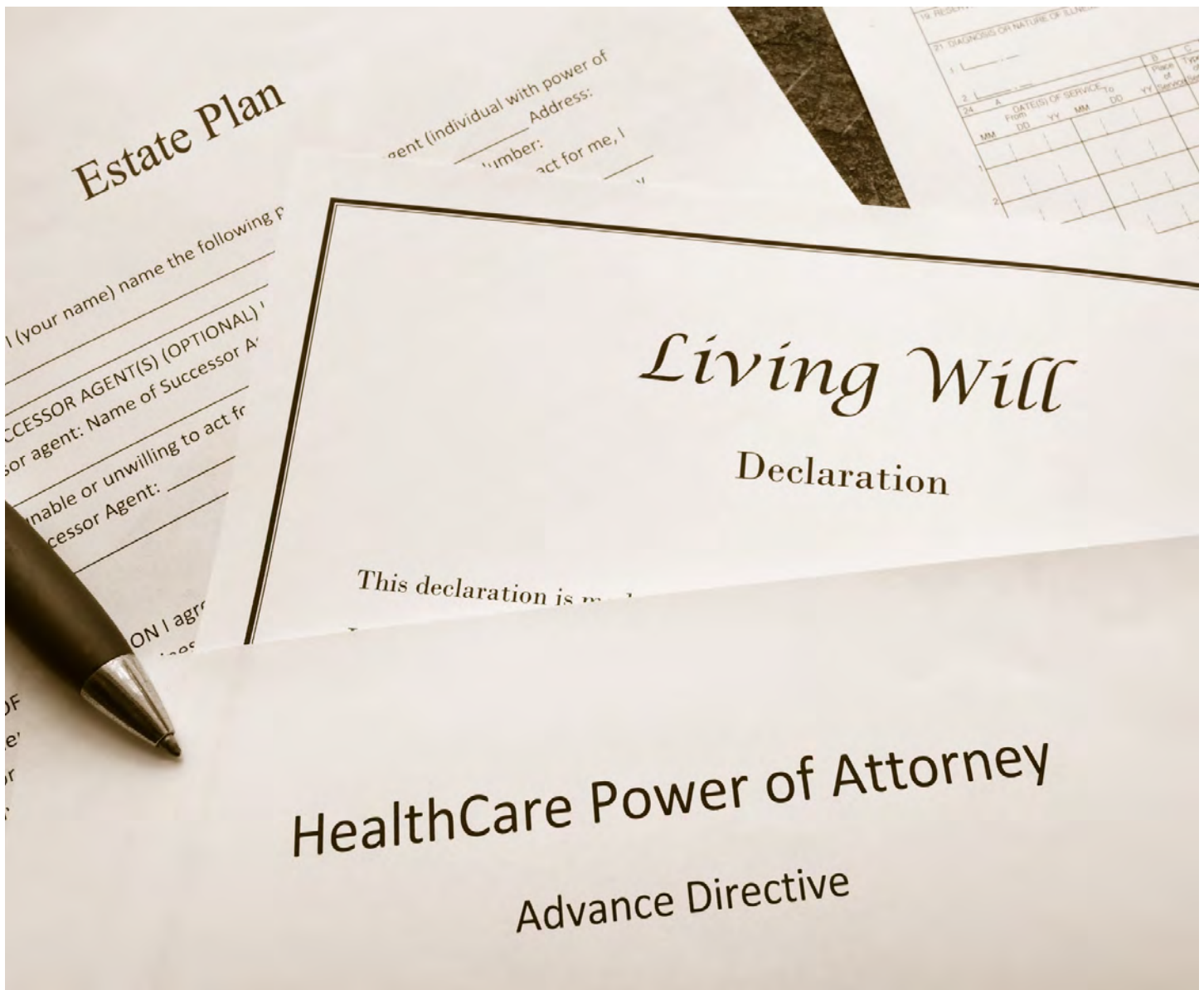
## Advance care planning

Advance care planning is a form of self-advocacy. You can take charge of your care and give yourself peace of mind by informing your healthcare team and your loved ones about the medical care you want to receive in the future—regardless of your health today or your prognosis. Advance directives are the tools used to communicate your choices when you are unable to do so for yourself. You have the right to accept or decline healthcare. An advance directive is a legal statement. It states your wishes for healthcare in the event you couldn't make your wishes known. It also can name a person whom you'd want to make decisions for you.

### *Why get an advance directive?*

- Without an advance directive, you may not get the healthcare you DO want.
- Without an advance directive, you may get healthcare you DO NOT want.
- Without an advance directive, your loved ones may have to make decisions for you. They may not know your wishes about healthcare. There may be conflict if your loved ones do not agree with another. An advance directive relieves them of this hardship.





### *Types of advance directives*

There are two types of advance directives. However, most states merge both types into one statement. The two types of advance directives are:

- **Living wills.** A living will states your wishes about the use of certain health treatments at the end of life. Examples include a feeding tube or pain medication. You must have a life-ending illness or be unconscious for the rest of your life for a living will to be followed.
- **Durable power of attorney.** In this report, you name a person who will make healthcare choices for you if needed. You can also note which treatments you do and do not want.

## *Advance directives do not:*

- Apply if you can make your wishes known.
- Discuss money or property. They are only for healthcare choices.
- Have to be followed if your wishes go against your doctor's morals, the health center's rules, or healthcare standards.
- Do not apply to EMS (emergency medical service) workers who respond to 911 calls, unless you have complied with your state's exceptions.

Don't wait to fill out your advance directives, even if the conversations today are difficult and decisions are hard to make. Discuss your decisions with your loved ones. Let them know you are making choices for yourself so they do not have to do so, which will alleviate some stress for them. You can always revise the documents if you change your mind or your situation changes. Also know that if you choose not to receive treatment or to stop treatment to control your cancer, palliative care continues to support your needs and any pain you are experiencing, while still honoring your values and goals.

Note: a lawyer does not always need to be present when you fill out these papers. However, a notary public may be needed. Visit [www.BagItCancer.org/resources](http://www.BagItCancer.org/resources) for more information on advance directives. Your doctor and/or another healthcare team member can assist you in obtaining and filling out the forms. Make sure you sign them (in front of a witness if required in your state) and then provide copies to your healthcare team, hospital, caregivers, and your family. 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.

## **Other Legal Documents**

The following legal documents have different functions than the living will and durable power of attorney described earlier. They are important documents related to your wishes outside of your health:

- A will tells how a person wants to divide money and property among his heirs. (Heirs are usually the surviving family members. Other people may also be named as heirs in a will.) It can also establish guardianship of minor children as necessary.
- Power of attorney appoints a person to make financial decisions for the patient when he or she can't make them.

It is generally recommended that an attorney prepare these important documents for you.

# After Active Treatment Ends

## Continuing Self-Advocacy

Now, and for the rest of your life, you must be self-aware, as others cannot, about subtle and not so subtle changes in symptoms such as pain, weakness, fatigue, or loss of appetite. Take advantage of cancer support services such as: pain management clinics, insurance and financial aid assistance, psychological counseling and therapy. If such services are unavailable, then advocate for support and referrals in order to receive these services.

- Stay informed about new research and developments in the treatment or late effects of your type of cancer. (see late and long-term effects on page 66)
- Attend community cancer programs or participate in teleconferences and webcasts that provide credible and current information.
- Ask your doctor(s) for a written summary of the treatment(s) received: drugs, dosage, amount of radiation, etc. Maintain this record with your health documents and present it to any new treating physician(s). (see Treatment Summary & Survivorship Care Plan on page 60 )
- Be vigilant about monitoring your own health. Have regular checkups and talk with your doctor about secondary prevention and monitoring for late effects of treatment

## What to Bring to Your Follow-Up Visits

- Bring someone with you to take notes or help with your questions.
- A tape recorder (or use an app on your smart phone)—ask permission first.
- Bring your questions and updates for your team. (see the *My Appointments Summary* form in *My Companion Guidebook*)

# Follow-up Care and Maintenance

When active cancer treatment ends, regular medical checkups are critical for your well-being. Who you see for follow-up cancer care is a decision that your oncologist and healthcare team will discuss with you, and is based on many factors, including what you need and who you feel comfortable with.

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 check to see if your cancer has returned or spread.

If your follow-up appointments are with your oncologist, it is 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 & Survivorship Care Plan if it was given to you by your oncology healthcare team (see Treatment Summary & Survivorship Care Plan on page 60)

## What to tell your doctor during follow-up visits

When you meet with your doctor for follow-up visits, it's important to talk openly about any physical or emotional problems you're having. Always mention any symptoms, pain, or concerns that are new or that won't go away. But keep in mind that just because you have new symptoms, it doesn't necessarily mean the cancer has come back. It's normal to have fears about every ache and pain that arises, but they may just be problems that your doctor can easily address.

Other things you should tell your doctor:

- Any 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're taking.
- Changes in your family medical history.
- Any emotional problems you're having, such as anxiety or depression.
- 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.



## Questions to ask about follow-up care

- Will I receive a Treatment Summary and Survivorship Care Plan? (see below)
- What follow-up care do I need? With whom and how often?
- Do I need any follow-up tests and how often?
- What symptoms or side effects should I report and to whom?
- Are there late or long-term side effects or health issues I should be aware of?
- Are there helpful survivorship programs or resources you can now recommend for me, my caregiver, and family members?

## Treatment Summary & Survivorship Care Plan

Your primary care doctor and other doctors not directly involved in your cancer care likely have limited knowledge of the treatment you received and of your related needs going forward. A summary of your cancer diagnosis and treatment you received or are still receiving, along with a plan for your follow-up care and screenings, will help them to better manage your recovery and overall health. You will also be better prepared to deal with your new healthcare needs. This information is part of your permanent health record for the rest of your life.

Near the end of your active cancer treatment or if you are moving to extended treatment to control your cancer, your oncologist or a member of your healthcare team should prepare a written Treatment Summary and Survivorship Care Plan for you. It is important that you request this document if it is not given to you.

Your healthcare team may use their own form or they may use one of the templates from the American Society of Clinical Oncology (ASCO) or Journey Forward. If your healthcare team does not routinely provide this report, visit the resource page on our website [www.BagItCancer.org/resources](http://www.BagItCancer.org/resources) for versions that they can complete for you.

The image shows a sample of a Treatment Summary and Survivorship Care Plan form. The form is divided into several sections:

- Follow-up Care Plan:** Includes checkboxes for "Planned for ongoing (adjuvant) treatment for cancer" (Yes/No), "Additional treatment name", "Planned duration", and "Possible Side effects".
- General Information:** Includes fields for "Patient Name:", "Patient phone:", "Patient DOB:", and "Email:".
- Health Care Providers (Including Names, Institution):** Includes fields for "Primary Care Provider:", "Surgeon:", "Radiation Oncologist:", "Medical Oncologist:", and "Other Providers:".
- Treatment Summary:** Includes sections for "Diagnosis" (Cancer Type/Location/Histology Subtype, Stage, Diagnosis Date), "Treatment" (Surgery, Radiation, Systemic Therapy), and "Familial Cancer Risk Assessment" (Genetic/hereditary risk factor(s), Genetic counseling, Genetic testing results).

The treatment summary portion should include:

- Date of diagnosis; type, stage, grade of cancer.
- Types of treatment (surgeries, chemo, radiation, other therapies, clinical trials, tests performed) with dates, location, responses to treatment, ongoing treatments.
- Any complications or side effects experienced.
- Contact information for doctors and healthcare team for continuing care.
- Genetic testing results (if applicable).
- Supportive care received (nutrition, psychosocial, physical therapy, complementary/integrative).

The follow-up care portion should include:

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

Keep copies for yourself in *My Companion Guidebook* and always give copies to all your doctors. Be sure the document is updated where needed as your health changes.

*You may need to schedule a separate appointment to review the Treatment Summary and Survivorship Care Plan and discuss any questions with a member of your healthcare team. Be sure to keep a copy for yourself.*

# 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.

## Fear of Recurrence

After treatment ends, one of the most common concerns survivors have is that the cancer will come back. The fear of recurrence is very real and entirely normal. Although you cannot control whether the cancer returns, you can control how much the fear of recurrence affects your life.

### Tips for coping with the fear of 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. 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. Ignoring them only allows them to become stronger and more overwhelming. 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.
- **Don't ignore your fears.** Telling yourself not to worry or criticizing yourself for being afraid won't 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. These may



include follow-up care appointments, the anniversary of your diagnosis, or someone else's cancer diagnosis. Sometimes, what you're worrying about may be unlikely. Talking to your healthcare team may help you figure out whether your fears are likely.

- **Don't worry alone.** 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.





- **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. This could include:
  - › Spending time with family and friends.
  - › Focusing on hobbies and other activities you enjoy.
  - › Taking a walk, meditating, or enjoying a bath.
  - › Exercising regularly.
  - › Reading a funny book or watching a funny movie.
- **Be well informed.** Most cancers have a predictable pattern of recurrence. However, no one can tell you exactly what will happen in the future. A healthcare professional who knows your medical history can tell you about the chances of the cancer returning. He or she 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 doesn't go away or gets worse, talk with your healthcare team.
- **Talk with your healthcare team about follow-up care.** One goal of follow-up care is to check for a recurrence of cancer. Your follow-up care plan may include regular physical examinations and/or medical tests to monitor your recovery. Keeping up with a regular schedule of follow-up visits can provide survivors with a sense of control. Find more information on developing a survivorship care plan on page 60.
- **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.

Even after your best efforts to cope, you might find yourself overwhelmed by fear or anxiety. The following feelings may indicate more serious anxiety or depression:

- Worry or anxiety that gets in the way of your relationships and daily activities or prevents you from going to your follow-up care appointments.
- Feeling hopeless about the future.
- Having trouble sleeping or eating well.
- Not participating in activities you used to enjoy.
- Having 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.



## 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.

## Coping with Physical Changes & 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.

*Palliative care specialists can help families and friends cope and give them the support they need during this phase of survivorship. Speak to your health care team about getting the care you need.*

## 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 about late and long-term side effects

- What can be done to manage any side effects that continue after treatment?
- What are the most common late and long-term effects that may develop based on my treatment plan?
- What should I do if I notice a late effect?
- What screening tests do you recommend based on my cancer history?
- Are there other doctors or specialists I should see, such as a cardiologist or endocrinologist?

## 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.

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. 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.
- **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.
  - › Make and keep all your doctor appointments, including with your primary care physician (PCP).

Ask your health care team which complementary therapies might be helpful to you to relieve stress and other symptoms or side effects you may be experiencing. (see complementary therapies on page 33)

## *Helpful Tip!*

Laughter can help you relax. When you laugh, your brain releases chemicals that produce pleasure and relax your muscles. Even a smile can fight off stressful thoughts.

# [6]

## Living with Chronic or Advanced Cancer

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### Living with Chronic Cancer

Chronic cancer is cancer that cannot be cured but that ongoing treatment (also called extended treatment) can control for months or years. As with other chronic diseases, such as multiple sclerosis or type 1 diabetes, the goal of extended treatment for cancer is to help patients live as well as possible for as long as possible. While living with cancer indefinitely is not easy, your healthcare team can help you manage the challenges of survivorship and extended treatment.

#### **Treatment for chronic cancer**

Chemotherapy, the use of drugs to destroy cancer cells, is often recommended for chronic cancers. You may receive the same drug or drugs that were initially used to treat the disease. Or you may receive a new drug or a combination of drugs. Many types of chemotherapy can now be taken as a prescription pill by mouth instead of intravenously, through a vein, at a doctor's office or hospital.

Other extended treatment options may include immunotherapy, targeted therapy, radiation therapy, or hormone therapy. Your doctor may also suggest a clinical trial that is studying an extended treatment. Your cancer might stay the same over time and not change during extended treatment. This means it is controlled. Treatment may be stopped if the cancer is in remission and continued if it starts growing again.

It is also possible for the cancer to go through cycles of growing, shrinking, or seemingly disappearing. If cancer continues to grow or spread, a different treatment may be recommended. It is important to remember that while chronic cancer can change, it will not go away completely. Sometimes treatment can no

longer control a cancer. If you choose to stop treatment, this does not mean you or your healthcare team have given up. Instead, your care is focused on relieving symptoms and allowing for additional support in all areas of your life. This is called palliative care or supportive care. (see Palliative care on page 75) It may be helpful to think about your treatment goals before making decisions about extended treatment. These may include:

- Living longer, even with cancer.
- Having fewer symptoms from cancer.
- Having fewer side effects from the treatment.
- Maintaining your physical and emotional abilities.
- Having a certain quality of life.

Your family and friends might have different ideas about your treatment. They might want you to have more aggressive treatment. Or they might try to keep you from having certain treatments. If this happens, talk to your healthcare team. They can help you talk with your loved ones, if you want them to.

## **Questions to ask your healthcare team about living with chronic cancer**

Regular and open communication with your healthcare team is important when you have chronic cancer. Consider asking them the following questions:

- What are my extended treatment options? What is the goal of each treatment?
- What clinical trials are open to me? Where are they located, and how do I find out more about them?
- How long do you think I can live with extended treatment?
- What side effects are possible based on the cancer treatment I receive?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- How long will I continue to receive extended treatment?
- How long do you think extended treatment can help me live?
- What specialists will I need to see?
- What follow-up tests will I need? How often will I need them?
- How will I know if the extended treatment is working or if the cancer is getting worse?
- If I'm worried about managing the costs of long-term cancer care, who can help me?
- Where can I find emotional support for me and my family?

# 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. 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 & Survivorship Care Plan if it was given to you by your oncology healthcare team. (see plan on page 60)

## Coping with chronic cancer

Having chronic cancer can make you feel angry, scared, anxious, or sad. Talking about your concerns is important, even when treatment is working well. Ask your healthcare team for resources that can help you cope. Options may include:

- Talking with a counselor about your situation.
- Joining an in-person or online support group.
- Finding a support buddy through a cancer organization.
- Learning relaxation and stress management techniques, such as meditation, yoga or deep breathing.
- Keep the conversation going with your healthcare team. They are there to help you. If you are not finding relief or are struggling with depression or distress, seek additional help right away.

## Advanced Cancer

Despite major advances in the treatment of cancer during the past few decades, recovery from cancer is not always possible. If a cure or long-term remission (no signs of cancer) becomes unlikely or impossible, the disease may be called advanced, end-stage, or terminal cancer. However, incurable does not mean untreatable. People with advanced cancer continue to have treatment options and can 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.
- Clinical trials. (see page 17)
- Palliative (supportive) care. (see page 75)
- Hospice care. (see page 76)





## Talking about your advanced cancer

Once you are diagnosed with advanced cancer, or your disease has progressed to this point, you will have a number of issues to talk about with your loved ones and your healthcare team. You'll need to discuss future steps and what to expect. 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. Also tell him or her 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.

- **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.

## **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.

## **Questions to ask your doctor 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. You can hope for the best while still being informed about your choices. 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.

***Your oncologist (or someone on your oncology care team) is the first person you should ask about palliative care. He or she 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.***

When you meet with your doctor, consider asking some of the following questions:

### *Questions about your cancer and treatment choices*

- How long can I live with my advanced cancer?
- Are there tests I should have now to better understand the extent of my cancer?
- What's the best we can hope for by trying another treatment? What's the goal?
- What are my treatment choices? Which do you recommend for me and why?
- Would a clinical trial be right for me?
- What kind of care will I receive to keep me comfortable if I decide not to have active treatment for my cancer?

### *Questions about symptoms and side effects*

- What are the possible side effects and other downsides of this treatment? How likely are they?
- How can I manage the symptoms of my advanced cancer or the side effects of its treatment?
- Can you refer me to a palliative care specialist to help me cope with my side effects?

## 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 in conjunction with your oncology care team to manage your care and maintain the best possible quality of life for you.*

## 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. Palliative care is also called comfort care, supportive care, and symptom management. 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.

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 about making the transition from cancer treatment to hospice care

- How do I decide whether to continue or stop cancer treatment?
- When should I consider having hospice care?
- How can I make sure I have the best quality of life possible—that I am comfortable and free of pain?
- Can I have hospice care in my home, or do I have to go to a special facility?
- How can I get help with financial and legal issues (for example, paying for hospice care or preparing a will or an advance directive)?
- How can I get help with my spiritual needs?



Talking about these questions may help you decide whether to continue or to end 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 figure out your needs and the needs of others close to you.

## 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 Practical Matters on page 55)



***“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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The supportive community of cancer survivors, caregivers,  
and friends of Bag It everywhere.



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