

# Survivorship: Living With, Through and Beyond Cancer



THE UNIVERSITY OF TEXAS  
**MD Anderson**  
**Cancer Center**

Making Cancer History®





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# To the patient and family

This booklet is for people who have been diagnosed with cancer and their families. If you have questions that are not answered in this booklet, ask your health care team.



Words that are in **bold** are defined in the glossary (page 27).





## Cancer Survivors

A cancer survivor is anyone who has been diagnosed with cancer, from the time of diagnosis and treatment through the remaining years of life.

At MD Anderson, your health care team provides you with the best possible care. Your team has specialists from every field related to the diagnosis and treatment of cancer. These specialists combine their knowledge and skills to develop your treatment plan and ongoing care.

If you have questions about MD Anderson's resources and services, ask a member of your health care team.



## Stages of Survivorship

There are 3 stages of survivorship.

- 1. Living with cancer begins with diagnosis.** The focus is on treatment, getting rid of the cancer, if possible, or controlling the cancer to the point where you can live with it long term. Treatment options include surgery, **chemotherapy** (chemo), **radiation** therapy, **immunotherapy** and medicines to manage side effects of the treatments. You may be asked if you would like to join a clinical trial in which new cancer medicines and treatments are studied. You may also be offered services to help you and your caregivers cope with emotional and practical concerns.
- 2. Living through cancer is the time after treatment.** This is when you are at risk of your cancer returning (**recurrence**). At this stage, you may feel relieved that treatment is over but anxious that you no longer see your cancer doctor on a regular basis. You may see your cancer doctor every 3, 4 or 6 months. This depends on your treatment plan. This is also a time of **rehabilitation**, especially if treatment included surgery that physically changed your body.
- 3. Living beyond cancer refers to post-treatment and long-term survivorship.** You may find your life returns to what you knew before you had cancer. Or, you may find that physical, psychosocial or financial concerns continue as a result of earlier treatments. This is often referred to as a **new normal**. During this stage, you may develop a plan for your ongoing health care with your cancer doctor and community health care provider.



## Communicate with Your Health Care Team

Your care at MD Anderson is based on a team or **interdisciplinary approach**. This means that specialists from many areas and disciplines help plan your treatment. The team includes your doctor, nurse, advanced practice provider (nurse practitioner or physician assistant), case manager, pharmacist, therapist, dietitian and social worker to name a few. You may meet with the members of your health care team one-on-one or in a group.

It is important that you communicate with your health care team. It is your right and responsibility, as a patient, to ask many questions. Ask questions until you understand what your health care team is saying. Be sure you know what you need to do to take care of yourself.

Here are a few tips to make a visit with any of your health care team members easier.

- Prepare a list of questions.
- Bring a friend or family member with you to take notes during the appointment.
- Report any new or different symptoms.
- Repeat instructions back to your health care team to make sure you have the right information.
- Speak up. Before you leave your appointment, make sure you address any questions or concerns.
- Follow up. If you have any questions after your appointment, contact your health care team.
- Keep a journal or a notebook to record your medical history in your own words and for your own use.

It is important to communicate with your health care team through every stage of your cancer experience. Some survivors need more information than others depending upon their diagnosis and treatment. If you have questions or concerns, do not hesitate to contact your health care team.

### **Guidelines for Follow-up Care**

After treatment, you may see your local doctor for follow-up care. Your local doctor may not know much about your cancer and treatment. Before you go home, ask your cancer doctor to give you a follow-up plan of care. Share this plan of care with your local doctor.

This plan should include:

- The type of cancer you had
- The treatment you had for your cancer



- Possible side effects of your treatment
- When to come back for follow-up visits (both at MD Anderson and with an outside provider, including primary care providers)
- The type of follow-up tests you need
- Tips for staying healthy

Most follow-up plans focus on the first 5 years after treatment. There are suggested yearly tests and procedures for each type of cancer. For suggested yearly tests and procedures, visit: [www.MDAnderson.org/Survivorship](http://www.MDAnderson.org/Survivorship).

## Late Effects of Cancer Treatment

Patients may have physical changes caused by the cancer itself or the therapies used to treat cancer. The effects of cancer may depend on your cancer type and treatment. The effects may differ over time. Health care teams think about these changes in different ways over time:

- Short-term side effects occur during treatment.
- Long-term side effects are those that begin during treatment and continue after the end of treatment.
- Late effects are symptoms or concerns that appear months or years after treatment has ended.

Some specific late or long-term effects may include the items described below. See pages 23 to 25 for resources at MD Anderson that may be able to help manage these issues.

Access the latest resources in MyChart:

- From your MyChart account, go to Resources and then My Education to view the content sent to you by your health care team.
- You can also search Education Document Library and Education Video Library to search for the topics of your choice.

### Bladder and Bowel Changes

Cancer and its treatment may change the way your bladder or bowels work. These changes can affect your everyday tasks.

You may have incontinence (a loss of urine) while coughing, sneezing, straining or sleeping. Depending on what bladder changes have occurred, you may need to see a wound, ostomy and continence (WOC) nurse or you may need a referral to a urologist.

Bowel changes may include **constipation** and **diarrhea**. Ask your health care team for a referral to a dietitian to learn more about how food affects your bowels.

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## High Blood Sugar

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Some medicines may cause your blood sugar levels to rise. If your blood sugar levels stay high after treatment ends, you may be at risk for **diabetes**. It is important that you talk about this risk with your primary care physician (PCP).

## Eyesight, Hearing, Speech and Dental Problems

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Cancer survivors should have regular checkups to help find or prevent any vision, hearing, speech or dental problems caused by cancer or its treatment. If you have any of these problems, ask your doctor to refer you to the right specialist.

### Eyesight

Radiation around the eye may increase the risk of eye problems, such as cataracts. Taking steroid medicines can also increase your risk for cataracts. For children, radiation to the bones near the eye may slow bone growth and stop them from forming correctly. In addition, other cancer medicines can lead to problems such as blurred vision, double vision or glaucoma. If you have problems with your vision during or after your treatment, your doctor may refer you to an eye specialist, called an ophthalmologist.

### Hearing

Certain chemo and antibiotic medicines may cause hearing loss. Radiation to the brain or ear may lead to hearing loss as well. Hearing aids may help correct problems caused by your treatment. If you have problems with your hearing, you may be referred to a hearing specialist, known as an audiologist.

### Speech and swallowing

After certain surgical procedures to the head and neck, your speech and ability to swallow and communicate may be affected. If you have problems with your speech, your doctor may refer you to a specialist, called a speech pathologist.

### Dental

Chemotherapy may affect tooth enamel and increase the risk of long-term dental problems. High-dose radiation to the head and neck area can change tooth development and cause gum disease. Chemo may also cause tooth decay or loss and decrease the amount of saliva (spit), causing a dry mouth. Mouth or throat soreness or ulcers may result from your cancer treatment as well. These side effects can be painful and can make it hard for you to eat, talk and swallow. You may be referred to a specialist in the MD Anderson dental clinic if you have problems with your teeth, gums or mouth.

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## **Fatigue**

Fatigue is the most common symptom experienced by cancer patients. It is treatable, but most patients do not report symptoms to their doctor. Cancer-related fatigue can affect your physical symptoms and your quality of life.

The stress of dealing with your cancer diagnosis can cause fatigue. Other causes include:

- Surgery, chemotherapy or radiation treatments
- Anemia due to chemo
- Sleep disorders
- Emotional distress
- Pre-existing medical conditions such as uncontrolled diabetes, thyroid problems, heart disease or rheumatoid arthritis

### **Coping With Fatigue**

Try these tips to boost your energy and fight fatigue.

- Exercise regularly.
- Do something active right after you wake up.
- Do not exercise in the evening.
- Keep a regular sleep schedule, even on weekends.
- Limit naps.
- If you must nap, keep it under 30 minutes.
- Do not read, watch TV or work in the bedroom.
- If you have not fallen asleep in 15 minutes, go to another room. Avoid mental stimulation and return to bed when you feel sleepy. If you still cannot fall asleep, get up again and repeat these steps.
- Avoid alcohol, caffeine, chocolate and nicotine in the evening.
- Turn off the TV one hour before bedtime. Listen to quiet music or take a warm bath instead.
- Keep a fatigue journal to help find patterns in your fatigue. This will help you prioritize your activities.

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## **Fertility After Cancer**

The inability to have children (infertility) can be a major source of distress for cancer survivors. Many cancer treatments can affect fertility in men and women or may make it hard for a woman to carry a pregnancy. Treatments that may affect fertility are:

- Chemotherapy
- Radiation to the brain or pelvic area
- Surgery in the pelvis

Some cancer patients are able to bank sperm, eggs, embryos or ovarian tissue before their cancer treatment begins. However, infertility treatments can be expensive depending on health insurance coverage.



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## Hormone Changes

Sometimes cancer treatment can change the body's natural hormones. For women, menstrual periods may suddenly stop (early menopause). Other side effects for women may include:

- Hot flashes
- Vaginal dryness
- Pain during sexual activity
- Fatigue
- Mild depression
- Problems sleeping

Men may have less testosterone. Men may also experience:

- Hot flashes
- Problems sleeping
- Fatigue
- Mild depression
- Loss of interest in sex
- Erection problems

Tell your health care team if you have any hormone-related side effects that bother you.

Women may need to make an appointment with their gynecologist or request a sexual health referral to the Gynecologic Oncology Center. Men may need a referral to meet with a doctor in the Endocrine Center.

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## Hypothyroidism

Some cancer treatments cause the **thyroid gland** to make too little thyroid hormone. This is called hypothyroidism. Symptoms include:

- Weight gain
- Constipation
- Dry skin
- Feeling cold all the time

You may be prescribed medicine to treat hypothyroidism.

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## Learning and Memory Problems

Cancer treatment may cause problems with learning and memory. For example, you may forget a word, name or thought when talking with someone. These changes are sometimes called **chemobrain**. You may experience chemobrain during or right after treatment. Cancer itself may also affect learning and memory. Memory loss may improve in long-term survivors.

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## Lymphedema

Lymphedema is swelling that occurs in the arms or legs. It is caused when lymph nodes are removed by surgery or damaged by radiation. Fluid builds up in the tissue in the arms and legs, which leads to swelling, pain and limited range of motion.

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Lymphedema can cause discomfort. It may cause clothes and jewelry to fit too tight. It may also increase your risk for skin infections. If not treated, the arm or leg can become permanently swollen, hard and heavy. Lymphedema may occur several months after surgery or radiation or many years later. If you notice swelling in your arm or leg, contact your health care team. Early treatment helps prevent problems.

## **Neuropathy**

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Neuropathy is a tingling, burning or numb feeling in the hands or feet due to nerve damage. Neuropathy can be caused by radiation, surgery and chemotherapy. It may improve when your treatment stops and may get better over time. It may also last for many years.

## **Organ Damage**

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Some cancer treatments can age or damage your heart, lungs, liver or kidneys. This damage may cause long-term health problems. These problems may appear as you age or have other health problems.

Other cancer treatments cause heart failure. Specific chemo medicines are harmful to the heart. Heart failure symptoms include:

- Shortness of breath
- Feeling weak and tired after regular activity or while at rest
- Chest discomfort
- Fast heartbeat

Your doctor screens you for heart failure during your treatment and may refer you to the Cardiopulmonary Center.

Certain medicines damage the lungs and airways. These include some antibiotics, chemo medicines or types of biotherapies. Common symptoms of lung damage include problems breathing, coughing or pneumonia. It is important to tell your doctor if you have any of these symptoms.

Some chemo medicines damage the liver. Symptoms of liver damage may include:

- Dark urine
- Pale stools
- Yellow eyes or skin
- Swelling or pain in your abdomen (stomach area)
- Flu-like symptoms
- Severe fatigue

When you take some chemotherapy medicines, you have regular blood tests to check how your liver is working.

Other chemotherapy medicines damage the kidneys. Symptoms of kidney damage include decreased urine flow or bladder irritation and bleeding. You may also have a change in urine color or a burning feeling while you urinate. Your doctor will check your kidney function closely.

If you have any of the above symptoms, tell your health care team.

## **Osteoporosis**

Osteoporosis (bone loss) occurs when bone mass is lost faster than it can be replaced. This results in weaker bones that may easily break. Some surgeries, cancer treatments, medicines or physical inactivity can increase your chances of bone loss or osteoporosis. For some cancer survivors, it is important to monitor your bone health through a bone density scan. Your doctor may recommend calcium and Vitamin D or other medicines called bisphosphonates. Exercise may also be prescribed. Weight-bearing physical activity (such as walking, dancing, stair climbing and jumping rope) stimulates production of bone-forming cells. Exercise also helps build muscles, which provide stability.

## **Pain**

Cancer pain takes many forms. It may be short-lived or long-lasting. It can also be mild or severe. Pain can affect your bones, nerves or organs. Each patient's pain is unique. Pain does not always mean the tumor has grown or returned. Your cancer or its treatment may cause pain. You may also have pain that has nothing to do with your illness or its treatment. Talk with your health care team about common signs and symptoms. Ask what you can do to reduce the chance of recurrence or second cancers. Also, see the **Guidelines for follow-up care** section on Page 5 in this booklet.

If the pain is sudden and new, like pressing chest pain, call 911 or go to the nearest hospital emergency room. Pain with fever, nausea, vomiting or bleeding, also needs emergency help.

## **Premature Aging**

Some of your treatments may cause health problems that are often seen in older people. These may include bone loss, arthritis (joint pain), early menopause, infertility and sexual health changes.





## Sexual Health

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When you find out you have cancer, your sexual health may not be high on your list of concerns. Because you are dealing with big choices and coping with stressful changes, the topic of sexuality may be the last thing on your mind.

Your sexual health is personal and your feelings and needs are unique. Cancer may impact your sexual health. These changes can be temporary or permanent and can include:

- Struggles to feel normal or attractive
- Loss of desire to have sex or difficulty being sexually responsive or intimate with your partner
- Physical changes to your body
- Hot flashes (men and women)
- Not being able to get or keep an erection (erectile dysfunction)
- Trouble enjoying sex because it is painful or vaginal dryness
- Trouble being able to have children (infertility).
- Concerns about the safety of a pregnancy after cancer

Intimacy is not just sex. It is also touching and closeness with someone. It means caring about someone. It includes sharing your hopes and feelings. Finding ways to be intimate with your partner during and after treatment is helpful. Talking with your partner is key to good sexual health during and after treatment. To learn more about how cancer can affect your sexual health and how to deal with these changes, talk with your health care team.

Patients may be unsure about how to talk about their sexual health with their health care team. If your health care team seems uncomfortable talking about your questions or concerns, ask to see a specialist. This could be a doctor or mental health professional trained to treat changes and issues related to your sexual health.

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## **Sleep Loss**

Being able to fall asleep or stay asleep can be a problem for cancer survivors. While sleeping, you may have hot flashes, night sweats, breathing problems or feel worried.

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## **Supportive Care**

Supportive care helps patients with advanced disease or severe side effects to reach the best possible quality of life. A team of specialists in the Supportive Care Center works together to assess and manage severe cancer-related symptoms.

## **Create a Self-Care Plan**

Self-care is important for everyone. Healthy choices should be a part of each day. Cancer survivors must focus on their health even if they feel fine after treatment.

A self-care plan is a tool to help you make healthy lifestyle choices. Your self-care plan can include your daily diet and exercise needs. This plan may lower your risk for illness and help improve your quality of life.

A healthy way of life may not always stop cancer from coming back or spreading. However, healthy choices can make you feel your best every day. Follow your plan and be sure to talk with your doctor if any problems arise. Together, you and your health care team will develop the best self-care plan.

Your self-care plan includes 9 parts:

- Physical activity
- Eat well
- Healthy weight
- Reduce stress
- Get regular checkups
- Avoid tobacco
- Limit alcohol
- Vaccinations
- Genetic counseling

Every self-care plan is different. Here are some healthy ways to start your self-care plan.

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## **Physical Activity**

Engaging in physical activity each day helps you feel your best. Examples of exercise include:

- Walking
- Swimming
- Cycling
- Gardening and outdoor work
- Playing sports





Based on your ability and goals, try to do the following:

- 150 minutes of moderate aerobic exercise each week  
OR
- 75 minutes of vigorous aerobic exercise each week  
OR
- Some combination of both vigorous and moderate aerobic exercise

If you were recently diagnosed with cancer or are currently in treatment for cancer, try to do aerobic exercise for at least 30 minutes at a moderate intensity 3 times a week. You can walk until you feel a little out of breath. Your heart should beat a little faster than normal.

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## Eat Well

MD Anderson recommends following the New American Plate guidelines developed by the American Institute for Cancer Research.

Take the following steps to maintain a healthy diet, manage your weight and reduce your risk of cancer:

### **Eat a plant-based diet.**

Eating a healthy diet can help you stay lean. Fill  $\frac{2}{3}$  of your plate with vegetables, whole grains and fruit. Fill the remaining  $\frac{1}{3}$  or less with lean animal protein like fish and chicken.

### **Limit red meat.**

Red meat has substances that are linked to colorectal cancer. Pork, beef, lamb, deer and buffalo are all red meat. Do not eat more than 18 ounces of cooked red meat per week.



### **Choose whole grains over refined grains.**

Whole grains are high in fiber, which can help you stay lean and lower your cancer risk.

### **Avoid processed meat.**

Hotdogs, sausage, lunch meats and other processed meats have cancer-causing substances. Eating these meats can damage your DNA, raising your colon cancer risks.

### **Choose plant-based proteins.**

You can add more plants to your diet without reducing your protein intake.

### **Avoid alcohol.**

Research shows that drinking even a small amount of alcohol increases your chances of developing oral, breast and liver cancers.

You can also meet with a dietitian to learn about good food choices.

## **Maintain a Healthy Weight**

Reduce your cancer risk by maintaining a healthy weight. Total body fat and visceral fat, the fat around your waist, increases the risk for up to 13 cancers. These include colorectal, breast (postmenopausal), endometrial, esophageal, pancreatic, gallbladder, kidney, liver and others. Body mass index and the size of your waist are 2 important numbers. If they are high, you may be at higher risk for certain cancers and other health problems.

## **Reduce Stress**

Stress is a part of life. Many changes are out of your control, but you control how you react to these changes. Learning to cope with stress can improve your health and make life more enjoyable. Use the following tips to help you cope with stress:

- Do fun things that make you laugh.
- Do things that make you feel relaxed.
- Take classes, like music or painting.
- Write in a journal.
- Pray or meditate.
- Attend support groups, seek counseling or share your feelings with close family or friends.
- Learn to accept what you cannot change.

## **Get Regular Checkups**

As a cancer survivor, maintaining your health is important.

- Take your medicines as directed.
- Have regular checkups.
- Get appropriate cancer screenings.
- Know what signs and symptoms to look for and when to call a member of your health care team.

During and after treatment, there are things you can do to improve your health. You may need to learn new ways to exercise, eat a healthy diet and reduce stress.

Talk with your care team about what to do to stay healthy.

## **Avoid Tobacco**

Tobacco use is the single most preventable cause of death in the United States. Smoking or using tobacco products puts you at risk for several types of cancer. Tobacco use increases the risk of your cancer coming back or getting a second type of cancer. When you quit smoking, your treatment outcomes may improve.

If you have tried quitting before but were not successful, do not give up. It is never too late to improve your health by kicking the tobacco habit. To speak with someone from the Tobacco Treatment Program, send an email to [QuitNow@MDAnderson.org](mailto:QuitNow@MDAnderson.org) or call the 2-QUIT line at 713-792-7848 (local) or 866-245-0862 (toll-free).

## **Avoid Alcohol**

According to the American Institute of Cancer Research, to prevent cancer it is best not to drink alcohol. Too much alcohol causes:

- Cirrhosis of the liver
- Obesity
- Heart disease
- Liver cancer and cancers of the gastrointestinal tract, such as cancer of the mouth and esophagus

Alcohol is also linked to breast and colorectal cancers. Alcohol and the link to cancer risk needs more research. The more alcohol you drink the greater chance you have of getting cancer and other types of diseases.

## **Vaccinations**

To prevent illnesses, there are specific vaccination recommendations for adults. These recommendations are very important for cancer survivors. Your immune system may have been impaired by your cancer treatments. It is important to stay up-to-date on vaccinations. The Center for Disease Control has recommendations for adult vaccines. It is important for cancer survivors to consider getting influenza (flu), pneumococcal, COVID, RSV and shingles vaccinations, depending on their age. For more information on vaccines, visit <https://bit.ly/VaccineByAge>

In most situations, it is recommended that cancer survivors follow the general guidelines for all adults, however it is important

to discuss with your health care team if there are any special guidelines for you. You should discuss all vaccines with your health care team. This includes any recommendations for new vaccines. In general, live vaccines (or vaccines made of active/living components of a virus) are not recommended for cancer survivors. Talk more about this with your doctor.

### **Vaccines for Cancer Prevention**

New advances have been made to develop vaccinations that can reduce your risk of some cancers. The vaccines are one way cancer survivors and their families can help reduce the risk of cancer.

Two vaccines have been developed which help prevent specific cancers. They are vaccines are Human Papillomavirus (HPV) and Hepatitis B virus (HBV).

Human Papillomavirus (HPV) is a group of common viruses. These viruses can cause non-cancerous cells to grow into cancer. HPV raises the risk of cervical, vulvar, vaginal, oral, anal and penile cancers. A vaccine is approved for adults up to age 45. It is recommended for men and women up to age 26 and for adults ages 26 to 45 after a conversation and shared-decision making with your doctor. Learn more at [MDAnderson.org/HPV](https://www.mdanderson.org/HPV).

Hepatitis B virus (HBV) can cause swelling and inflammation of the liver. If left untreated, it could lead to liver cancer. In many cases, hepatitis B can be prevented. The best form of prevention is to get vaccinated. Hepatitis B vaccinations can be given to everyone from infants to adults. Talk with your doctor about getting a vaccination.

### **A note for survivors who have had cellular therapy:**

The body's immune system fights infection. After a stem cell transplant (SCT) or other forms of cellular therapies, the body's defenses are very low. Immunity from any childhood vaccinations you once had are greatly reduced or even lost. If you received stem cells from a donor, the donor's vaccinations do not transfer to you. Therefore, you are at higher risk of infection until your immune system gets stronger. You need protection from childhood diseases, flu and a certain type of pneumonia. Your health care team works with you on a schedule for these vaccinations.

## Genetic Counseling

Consider seeing a genetic counselor for a cancer risk assessment if your personal or family history includes signs of hereditary cancer. Hereditary cancers tend to differ from non-hereditary cancers. New links between our genetics and cancers are discovered all the time. It is important to discuss your family history with your health care team, even if you are no longer being treated. It is possible new information could help you or your family members better understand your cancer risk.

Signs that cancer may be hereditary include when:

- A cancer diagnosis occurs at a younger age than in the general population (often younger than age 50)
- More than one person from the same side of the family have the same or related types of cancer
- Cancer develops in more than one site in the body

You may also consider genetic counseling if you have any of the following:

- Breast or ovarian cancer diagnosis with Ashkenazi Jewish ancestry (Eastern or Central European Jews)
- Polyposis (multiple polyps in the colon, stomach or small intestine)
- Certain rare cancers, such as male breast cancer, retinoblastoma, medullary thyroid cancer or pheochromocytoma/paraganglioma
- A family member with a genetic test that confirms a hereditary cancer syndrome





## Psychological, Social, Emotional and Spiritual Impact of Cancer

As a survivor, cancer and its treatment affects more than your body. You may have psychological, social, emotional and spiritual changes as well. These changes affect your quality of life and may continue to be felt after your treatment is over.

There are no guidelines on how to be a survivor. These changes may come and go and may be different during and after treatment.

### **Psychological, Social and Emotional Changes**

You may have fear, anxiety, anger, guilt, grief or depression. These are normal feelings. You may see a change in your self-image or self-esteem. You may also have a change in family roles.

It is normal to be angry when you have cancer. It affects your job, school and relationships. Let your anger out in a positive way. Some survivors find it helpful to talk with a counselor, support group or a good friend. Other survivors find it helpful to write, paint or draw to express their anger.

Feeling uneasy or anxious is common when dealing with cancer. You may have many questions about your health, finances and loved ones. For example:

- How serious is my illness?
- Will my health insurance cover my care?
- Who will take care of my family?

It is common to feel sad and depressed about your illness. At some point, many cancer survivors feel depressed. Talk with your health care team if you feel bad for more than a couple of weeks or feel so sad that you cannot do normal, everyday things.

It is common for cancer survivors to have fears. You may fear the unknown. You may also fear that your cancer will come back. Fear can be good and bad. Fear is good if it makes you talk with your doctor when you have a new ache or change in your body. Fear is bad if it keeps you from making decisions.

Grief is a normal process that helps people heal after loss. Many losses may come with cancer. These losses can be simple or complex. Losses can include a change in your health and independence. You may want to avoid feelings of grief. Instead, it is important to get help.

During treatment, you may see changes to your body. Some patients have extreme weight loss or gain. Marks on your body, such as radiation tattoos, eye patches or scars are hard to deal with for some people. You may experience a feeling of loss.

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It may be a loss of a body part (amputation) or loss of bladder control. If you have a urostomy (an opening to get rid of urine) or colostomy (an opening to get rid of body waste) you may feel unsure in public. You may have a loss of feeling like a man or a woman. You may not feel comfortable being intimate with your partner. This is often common for women who have had a mastectomy (removal of a breast) or men who have had a prostatectomy (removal of the prostate).

Some survivors feel a sense of guilt for surviving cancer. You may ask, "Why am I the one to survive?" You may then struggle with another question, "Since I survived, what is the meaning of my life now?" This may cause you to take a closer look at your life. You may rethink your goals, how you want to live your life or spend your time. If your sense of guilt lasts for more than a few months, there are people who can help you talk through your feelings.

To cope with your emotions, try the following:

- Write down your thoughts and feelings in a journal.
- Share your concerns with a friend or support group.
- Do yoga, tai chi or meditate.
- Learn the difference between normal body changes and serious changes.
- Know when to call your doctor.
- Connect with a counselor for strategies to think in a positive way.

## **Spiritual Changes**

Like many survivors, you may find that your life takes on new meaning after cancer. Your values may change. Your ties to others may become stronger. Some survivors rely on their spiritual beliefs to help them through illness. On the other hand, you may feel abandoned. You may question, "Why me?"

More and more survivors follow a holistic approach. A holistic approach considers the whole person — body, mind and spirit. There are many places to learn more about the ties among body, mind and spirit.

Spirituality means different things to different people. It is about having feelings of faith, hope and love. You may look for life's meaning and purpose or you may want to reach out and help others. Many people also follow a religion and join a community of a certain faith. These and many other ways show how people connect with each other and life in a spiritual way.



## **Return to Daily Life**

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You may have a hard time getting back to your day-to-day life and work. This may cause stress.

Some worries may include:

- Risk of infection
- Lack of energy during the day
- Chemobrain

You may deal with life-and-death questions. This may cause you to feel alone. It may help to talk with other survivors. To be matched with a survivor, call [myCancerConnection](#), a free program offered at MD Anderson.

## **Talk about Your Cancer with Others**

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In the past, most people did not even want to use the word cancer. While times have changed, you may fear you will be seen differently. You may be afraid to tell your employer or coworkers about your treatment. You may fear losing your job or health insurance. This fear adds to the emotional stress of having cancer.

One of the hardest things to face is how the people closest to you will react. Often friends, coworkers and family members do not know how to talk with you about their own fears. Some may use humor to avoid serious talk about cancer. Others may not know what to say or how to act. Some may pretend nothing has happened. This can lead to silence. With this silence, you may begin to feel abandoned. Some others may continue to treat you like a sick person well after your treatment has ended. They may ask you questions about your health. Since cancer can be a long-term illness, talking about it early is an important step. You do not need to share anything that makes you uncomfortable.

## Financial and Legal Impacts of Cancer

Money issues often have a major impact on survivors. Survivors can be left paying for some or most of their treatment costs. If you are the major wage earner, there may be little or no income during treatment. Insurance coverage might also change after cancer treatment. Benefits may be reduced or lost. As a result, you and your family may face increased financial responsibilities.

Many families need financial help after cancer treatment. For questions about the cost of your care or your bill, talk with the Financial Clearance Center or Patient Business Services at MD Anderson. If you cannot cover the costs of your care and you are a Texas resident, ask for a Patient Financial Assistance Application.

A third-party eligibility vendor is available to discuss and help you apply for Texas Medicaid or disability. This service is free of charge. If you do not live in Texas, talk with your social work counselor. They will tell you about programs that may help based on your specific needs.

Legal issues are also important to survivors. You are encouraged to know your rights as a cancer survivor. Survivors should plan for the future. It is never too soon to make financial and legal plans. Prepare legal documents that make your wishes known. Proper planning makes sure your wishes are followed and eases the stress of decision making for your loved ones.

## Career Counseling

Counselors in the Adolescent and Young Adult (AYA) program help active patients and survivors ages 15 to 39 enroll in college, find financial aid, explore career and vocational opportunities and prepare for job interviews. There are resources for cancer patients who need help with school or vocational programs. Learn more at [MDAnderson.org/AYA](http://MDAnderson.org/AYA).

## Advance Care Planning

Advance care planning is an ongoing process of talking about your goals, values and wishes in terms of your health care. You are encouraged to discuss these topics with your caregivers, friends, those who represent you and your health care team.

It helps to have these talks with your caregivers and health care team early so that you can think through your options and identify what is most important to you. In the event that your caregiver or doctor needs to make choices when you are ill, they can do so with confidence that they are following your wishes.



## **Advance Directives**

Completing advance directives is one way for you to make your wishes known about medical treatment before you need such care. Advance directives allow you to state your choice for health care if you become too sick or unable to make decisions. There are 3 kinds of advance directives in Texas:

### **Medical Power of Attorney**

This form allows you to appoint someone you trust to make health care choices for you if you are unable to do so for yourself.

### **Living Will**

This form allows you to tell people what kind of medical care you would like to have or avoid if you cannot speak for yourself.

### **Out-of-Hospital Do Not Resuscitate (OOHDNR) Order for Adults**

An order signed by a doctor allows you to refuse life-sustaining treatments when outside the hospital. If you are admitted to the hospital and do not wish to have life-sustaining treatments, let your doctor know so an in-patient DNR order can be signed for while you are in the hospital.

You can always change your mind and re-evaluate your choices as needed. Speak with a social work counselor for more information on advance directives.

## **Referrals and MD Anderson Support Services**

You may need referrals to the following departments or clinics to address specific side effects or concerns.

**Adolescent and Young Adult (AYA) Clinic:** serves patients ages 15 to 39, whether in active treatment or post-therapy survivorship. Patients have access to counseling and care that helps them manage the milestones and challenges that come with being a cancer patient as a young adult.

**Bone Health Clinic (Endocrine Center):** provides treatment for metabolic bone disorders or bone loss caused by cancer treatments. Staffed by a multidisciplinary team of experts, the clinic evaluates and treats conditions that include osteoporosis, low bone mass, fractures, loss of height and Vitamin D deficiency.

**Cancer Prevention Center:** offers a range of services to help you learn how to reduce your cancer risk or to detect cancer early — when it's most treatable. Cancer screening exams are based on age, gender and disease risk. MD Anderson also offers risk assessment, risk reduction and diagnostic evaluation services, as well as cancer screening services for the most common cancers.



**Cardiology Center (Cardiac Late Effects):** treats cardiac and pulmonary conditions that existed before the patient came to MD Anderson as well as those brought on by cancer and its treatments.

**Endocrine Center:** addresses long term endocrine effects, that may arise in patients due cancer or its treatment.

**Fatigue Clinic (Internal Medicine):** provides a comprehensive approach to managing fatigue by assessing each patient's fatigue burden and developing a customized program of care designed to ease fatigue and help patients cope with cancer treatment.

**Gynecologic Oncology Center:** focuses on the physical aspects of fertility preservation and reproductive options. Your emotional and psychological needs are also very important and are addressed.

**Genetic Counseling:** provides information and support about genetics and inherited conditions to an individual or family. The goal of genetic counseling is to provide clear and clinically relevant information about genetic risk factors in a way that both supports and educates.

**Healthy Living Clinic (Cancer Prevention Center):** health educators provide detailed guidance on how to reduce your cancer risk through diet and exercise.

**Integrative Medicine Center:** offers therapies that reduce patients' stress and anxiety and improve their physical, mental and emotional well-being. In consultation with your MD Anderson team, comprehensive approach to your cancer care is designed.

**Lymphedema therapy (Rehabilitation Services):** offers services for the prevention and treatment for edema and lymphedema, including manual lymphatic drainage and custom garment fitting

**Neuro-Oncology Center (Neuropathy management):** addresses central and peripheral nervous system conditions that may affect cancer patients. The center can also diagnose and treat cognitive and behavioral effects of cancer or help patients learn ways to minimize cancer's impact on their quality of life.

**Nutrition Counseling (Clinical Nutrition):** promotes comprehensive nutrition care for our patients.

**Pain Management Center:** works to find the best care for each patient experiencing chronic (ongoing) pain related to their cancer.

**Psychiatry Center:** offers personalized support services to cancer patients and their caregivers, all designed to help maximize quality of life. Services include stress management, cognitive behavior therapy, sexual counseling and family counseling.

**Rheumatology/Immunology (Internal Medicine Center):** addresses diabetes, heart disease, hypertension, thyroid dysfunction, rheumatic diseases, allergy and immunology disorders and other metabolic disorders that have been brought on by cancer or its therapy.

**Smoking cessation (Tobacco Treatment Program):** offers tobacco-cessation services, including behavioral counseling which occurs in person, virtually, or by telephone. Also offers several tobacco-cessation medicines, at no cost to MD Anderson cancer patients who currently use tobacco (e.g., cigarettes, smokeless tobacco) or those who quit using tobacco within the past 12 months.

**Social Work:** helps patients and caregivers cope with the impact and changes that result from a cancer diagnosis. Licensed counselors discuss advance care planning, adjusting to your diagnosis over time, financial concerns, safety concerns and talking with children or family. Services are free, can be provided in person or over the phone and do not require a referral from a doctor or medical team.





## Resources

**askMDAnderson:** Health information specialists can answer your questions about MD Anderson resources. Clinical nurses are available to answer symptom-related clinical questions after clinic hours and on the weekends. 877-632-6789

**The Learning Center:** A patient education library that provides current and reliable information on cancer prevention, treatment, coping and general health. [MDAnderson.org/TLC](https://MDAnderson.org/TLC)

**myCancerConnection:** MD Anderson's cancer support community offers free, one-on-one support to patients, caregivers and survivors regardless of where they receive treatment. Trained survivor and caregiver volunteers are available to share their cancer experience with you. Matches can be requested based on diagnosis, treatment or other related cancer experiences. Contact through MyChart or by calling 800-345-6324. Learn more at [MDAnderson.org/myCancerConnection](https://MDAnderson.org/myCancerConnection).

**Patient Education Recommended Resources:**  
[MDAndersonTLC.Libguides.com/Survivorship](https://MDAndersonTLC.Libguides.com/Survivorship)



## Glossary

**Antibiotic:** Medicines used to treat infections caused by bacteria or fungi. Antibiotics come from living organisms, such as mold.

**Cataracts:** A cataract is a condition where the lens inside the eye becomes cloudy. When this happens, light entering the eye does not properly focus. This results in blurry vision that cannot be corrected with glasses or contact lenses.

**Chemobrain:** Changes in thinking skills from cancer or chemotherapy (chemo). Changes may range from mild to severe.

**Chemotherapy:** Medicines that kill cancer cells. It works throughout the entire body, killing cancer cells that have spread to parts of the body far away from the original tumor.

**Constipation:** When food moves too slowly through the body making it difficult or painful to have a bowel movement

**Diabetes:** Diabetes is a disease in which your blood sugar levels are too high. This may cause blindness, heart disease, kidney failure and amputations (the loss of a body part).

**Diarrhea:** Watery and frequent bowel movements.

**Glaucoma:** A disease caused by an increase in eye fluid pressure that damages the eye's optic nerve. Without treatment, glaucoma can cause blindness. There may be no symptoms of glaucoma, but a yearly eye exam can detect it.

**Immunotherapy:** Cancer treatment which uses the body's own natural defenses to fight cancer.

**Infertility:** When a person is not able to have children.

**Interdisciplinary approach:** When specialists from different areas and disciplines are involved in treatment planning.

**New normal:** The life you experience after cancer may be different from the life you experienced before you were diagnosed. It is a "new normal."

**Psychosocial changes:** These changes affect how you think, feel, behave and interact with others, and how you find meaning and purpose in life.

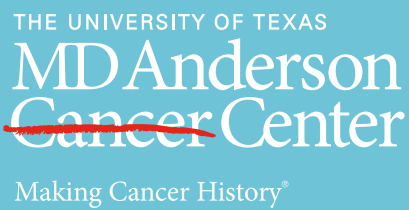
**Radiation:** Treats cancer by using high-energy rays. It pinpoints and destroys cancer cells in the body. Sometimes it is called radiotherapy. Although radiation is similar to an x-ray, the dose is much higher and is given over a longer time.

**Rehabilitation:** A process to improve physical activity lost to injury or disease. It helps you regain your strength, relearn skills or find new ways of doing things.

## Notes

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