



OhioHealth Cancer Care

# *My Cancer Planner*



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Name

Phone Number

Email

*Cancer is a unique experience for everyone, but at OhioHealth, you have a partner who will stand shoulder to shoulder with you, guiding you every step of the way.*

No matter which OhioHealth care site you choose for treatment, you will be supported by a team of healthcare professionals that includes physicians, nurses, therapists, dietitians, pharmacists, social workers, chaplains and volunteers. Beyond treating your cancer, this team will help you better understand your diagnosis and connect you to valuable resources that can ease your transition into life with cancer and survivorship.

At OhioHealth, we treat more than just cancer. We are treating people with cancer. We are treating your cancer. We hope the information in this guidebook helps you better understand all of the resources available to you at OhioHealth, and that it will be a useful tool along your journey.

As a certified member of MD Anderson Cancer Network®, a program of MD Anderson Cancer Center, OhioHealth can call on the expertise of world-renowned leaders in cancer care to provide input on your case and help develop your treatment plan.



If you would like to be connected with a OhioHealth patient navigator or talk to an oncology-trained nurse about your cancer diagnosis, treatment or survivorship, please contact OhioHealth CancerCall at (614) 566.4321 or toll-free at 1 (800) 752.9119. We are available Monday through Friday, 8 a.m. to 5 p.m. You, your family or your friends may also visit us online at [OhioHealth.com/Cancer](https://www.ohiohealth.com/Cancer).

### Patient Navigation

*No one should face cancer alone. We make sure our patients don't have to.*

OhioHealth provides patient-centered care through our patient navigation program, which goes beyond clinical treatment. Our patient navigators help ensure patients and their families find the various resources, treatment and support services they need.

Our patient navigators have one goal – to improve our patient's experience and quality of life. We are here to help guide patients and provide the resources, services and support they need. Patient navigators:

- + Educate you and your family about your cancer and what to expect during and after treatment.
- + Assist with communication between you and your care team.
- + Coordinate care with your managing physicians and interdisciplinary team.
- + Connect you with resources that provide education, advocacy and emotional support.
- + Address questions and concerns specific to your type of cancer or treatment.
- + Connect you to resources for wigs, hats, scarves, clothing and prosthetic devices.

*To reach your patient navigator, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.*

## My Team Directory

Team Member	Name	Phone Number	Address
Patient Navigator			
Medical Oncologist			
Medical Oncology Nurse			
Radiation Oncologist			
Radiation Oncology Nurse			
Surgeon			
Surgery Nurse			
Primary Care Doctor			
Doctor			
Doctor			
Doctor			
Doctor			
Pharmacy			
Social Worker			
Counselor			
Dietitian			
Medical Supply Source			
Other			

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.

## OhioHealth is a certified member of MD Anderson Cancer Network®



OhioHealth is a certified member of MD Anderson Cancer Network®, a program of MD Anderson Cancer Center. We are proud to be the first hospital system in Ohio to team up with MD Anderson Cancer Network, a world-renowned leader in cancer care, to make great cancer care at OhioHealth even better. This collaboration allows us to combine the best of what we provide locally with the expertise of the nation’s leading cancer center.

Through this relationship, our OhioHealth cancer specialists – certified by MD Anderson Cancer Network – have access to nationally recognized cancer care protocols and best practices. They can also consult with MD Anderson cancer specialists to help develop treatment recommendations.

At OhioHealth, you can be confident in the exceptional quality of your cancer care. You are in the hands of cancer specialists who follow MD Anderson Cancer Center’s nationally recognized best practices for:

- + Patient outcomes.
- + Quality care assurances and protocols.
- + New technology, treatments and clinical research.
- + Integrated patient care and prevention.
- + Specialized treatment for your type of cancer.
- + Access to peer-to-peer consultations and clinical trials.



### What is MD Anderson Cancer Network?

MD Anderson Cancer Network is a program of MD Anderson Cancer Center. The network is designed to advance the institution's mission of eliminating cancer by delivering MD Anderson expertise to community health providers. The network includes mission-aligned hospitals and healthcare systems across the United States committed to elevating the quality of cancer care in their communities.

### How does this relationship benefit patients like me?

This relationship helps OhioHealth further elevate its quality clinical care through access to expertise at the top cancer hospital in the country, while still providing you with direct care from your local OhioHealth providers. Additionally, in rare cases, your care team here in Ohio, including your primary care physician, will consult with MD Anderson specialists in Houston to develop a comprehensive treatment plan that is right for you.

### Which MD Anderson services will I be able to access as a result of this relationship?

Your care team has access to nationally recognized best practices and protocols established by MD Anderson and adopted by OhioHealth. MD Anderson is one of the nation's original three Comprehensive Cancer Centers, pioneering the National Cancer Institute guidelines that set the standard of cancer care today.

### Will the OhioHealth cancer specialists who are certified by MD Anderson Cancer Network accept my insurance?

Our policies on insurance have not changed as a result of this relationship. OhioHealth facilities generally accept most major health insurers in the Ohio region. Visit [OhioHealth.com/Insurance](http://OhioHealth.com/Insurance) to view insurance plans for the OhioHealth location you are visiting.

### Are all OhioHealth hospitals that provide cancer services and cancer specialists certified by MD Anderson Cancer Network?

Because OhioHealth is the largest health system to be certified to date, a rolling certification process for physicians and hospitals is taking place. While not all OhioHealth cancer specialists will be certified, our priority to connect you to the most appropriate cancer specialist for your type and stage of cancer remains the same.

Contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119 to learn if your OhioHealth hospital is certified by MD Anderson Cancer Network.

### Does this mean I will be seen by MD Anderson specialists? Will I be transferred to Texas for care or have a teleconference with MD Anderson specialists?

In most cases, no. Your care will be provided by an OhioHealth cancer specialist, right here in Ohio. In rare cases, you may be referred to an MD Anderson physician in Houston for further treatment.

### How will this affect my primary care physician? Will he or she be able to refer me to an OhioHealth cancer specialist certified by MD Anderson Cancer Network?

Your primary care physician will continue to collaborate with OhioHealth cancer specialists as usual. The OhioHealth and MD Anderson Cancer Network relationship just brings additional expertise to your care team, all focused on you.



# The OhioHealth Genetic Counseling Program



### Hereditary Cancer Risk Assessment

When several members of a family have had the same or related cancers, there is a greater likelihood that the risk for cancer is hereditary. The only way to know for sure is through a cancer risk assessment.

The OhioHealth Genetic Counseling program is your source for a hereditary cancer risk assessment. We can help you identify if the cancer in your family is hereditary and provide guidance to you and your physician so you can make the best choices for your ongoing care.

### Who needs genetic counseling and testing?

Individuals with any of the following should schedule an appointment with a genetic counselor:

- + Cancer diagnosed under the age of 50.
- + More than one cancer in the same person.
- + Two or more relatives with the same type of cancer on the same side of the family, especially if the cancer occurs at a young age.

- + Ovarian, primary peritoneal or fallopian tube cancer at any age.
- + Male breast cancer at any age.
- + Pancreatic cancer at any age.
- + Metastatic prostate cancer at any age.
- + Rare cancers or tumors.
- + Ten or more colorectal polyps (especially adenomas).
- + Cancer and Ashkenazi Jewish (Eastern European) ancestry.
- + Clustering of cancer in a family (such as breast and ovarian, or colorectal and uterine).

*Remember, even if you don't have a family history of cancer, you still may have hereditary risks for cancer. If you are concerned about your history, talk with your physician or contact the genetic counseling office.*

## How we complete your assessment

### What will happen at my appointment?

When you meet with a genetic counselor, you will discuss:

- + The likelihood that you and/or your family's history of cancer is hereditary.
- + Whether or not genetic testing would be helpful for you and/or your family.
- + How your family history and/or genetic test results may change your cancer screenings and risk reduction options.

Genetic testing is a choice. If you proceed with genetic testing, we will coordinate testing for you, which can be completed at the time of your appointment.

### After your appointment

We will discuss your results with you in detail, and send you and your referring physician a detailed letter that includes the results and recommendations. At your request, we will send a copy of this letter to other physicians or family members.



## I think cancer genetic counseling may be right for me and my family, but I have questions about cost.

### Will my insurance cover genetic counseling and testing?

- + The cost of genetic testing varies based on the type of test ordered and the laboratory performing testing. Most labs have a policy in place that ensures you will be notified if your out-of-pocket cost is greater than a certain amount (often \$100) and will give you the opportunity to cancel testing if desired. The majority of our patients pay less than \$100 out of pocket for testing when medical criteria is met.
- + For those with high-deductible insurance plans, or when insurance does not cover genetic testing, we can arrange self-pay options that often range between \$250–\$400.
- + Genetic counseling is billed as a facility fee, and we have found that most insurance plans cover this visit.

### What if I don't have insurance?

As a not-for-profit charitable organization, OhioHealth provides a generous charity care policy and provides genetic counseling regardless of a person's ability to pay. If testing is recommended, additional programs may be available to cover some or all of testing costs.

## I think cancer genetic counseling may be right for me and my family, but I have questions about future insurance coverage if I have a hereditary cancer syndrome.

### Can I lose my health insurance if I have a hereditary cancer syndrome?

There are state and federal laws in place to protect you. The Genetic Information Nondiscrimination Act (GINA) is a federal law passed in 2008, which applies to group health insurance plans and self-insurance plans.

### GINA states that genetic information cannot be:

- + Used to determine health insurance eligibility, coverage or cost.
- + Considered a pre-existing condition.
- + Requested by your employer or used to determine employment decisions (such as hiring, firing or promotions).

For more information, visit [GINAHelp.org](http://GINAHelp.org).

### What about disability and life insurance?

There are no laws to protect you against disability and life insurance discrimination. Life insurance companies could use genetic test results to determine rates. These companies do ask for your personal and family history information to determine your risk level. Some people consider obtaining life insurance policies before having genetic testing.

## I think cancer genetic counseling may be right for me and my family and I would like to schedule an appointment.

Your medical and family history are needed before scheduling an appointment. Please provide this information online at [Assessments.OhioHealth.com](http://Assessments.OhioHealth.com) or contact the OhioHealth Genetic Counseling program at (614) 788.4640. We will schedule your appointment after you submit your history information. Cancer genetic counseling is available at several locations in Columbus and central Ohio.

For genetic counseling locations, contact OhioHealth Genetic Counseling at (614) 788.4640.

# OhioHealth CancerCall

Connecting you with OhioHealth cancer care expertise



OhioHealth CancerCall is an easy-to-use single access point to connect with your patient navigator or obtain physician referrals to OhioHealth cancer specialists. OhioHealth CancerCall is staffed by oncology nurse navigators who can provide the most up-to-date information on cancer screenings, programs and services throughout OhioHealth and the community.

Contact CancerCall at (614) 566.4321 or 1 (800) 752.9119 Monday through Friday, 8 a.m. to 5 p.m.

## Manage your appointments

- + Schedule appointments online.
- + Fill out health forms prior to coming in for a visit.
- + View your past and upcoming appointments.

## Request prescription refills

- + Request a medication renewal and select a pharmacy. Your physician's office will respond with confirmation or ask you to schedule an appointment.

## Stay in touch with your physician's office

- + Get medical advice and answers to questions that are not urgent.
- + Send secure messages to your physician's office. When the staff replies, you will receive an email directing you to log in to OhioHealth MyChart.

## View your medical information online

- + Review your medications and medical history.
- + Review certain test results online.
- + Review your physician's follow-up instructions.
- + Link your family's accounts to yours to conveniently keep track of your entire family's health information and appointments, all in one place.

## Activate your OhioHealth MyChart Account

*If you have a scheduled appointment, you may already have an OhioHealth MyChart account.*

- + Activate your account on your phone
  - You can access OhioHealth MyChart from your iPhone or Android device.
  - Download the OhioHealth app from your app store.
  - Inside the OhioHealth app, click Create an Account.
  - If you received an activation code from your physician's office, click Enter My Activation Code.
  - If you don't have an activation code, click Get Started With No Code.
- + Activate your account on your computer or tablet
  - Get your activation code by calling your physician's office or asking the medical receptionist when you arrive for an appointment.
  - Go to MyChart.OhioHealth.com and follow the instructions to sign in.



## Download MyChart

You can download the OhioHealth app from the Apple App store or Google Play.

## We have social work navigators at multiple locations who can connect you with the resources below.

### General Information

*American Cancer Society – Cancer.org or 1 (800) 227.2345*

- + Education and support

*CancerCare – CancerCare.org or 1 (800) 813.4673*

- + Information and support online or by phone

*Cancer Support Community – CancerSupportCommunity.org or 1 (888) 793.9355*

- + Information about nutrition, mind-body classes, individual counseling and support groups

*Leukemia and Lymphoma Society – LLS.org or 1 (888) 557.7177*

- + Information, education and support for blood cancer patients

### Financial Assistance

*Cancer Financial Assistance Coalition – CancerFac.org*

- + Coalition of organizations that provide financial assistance to cancer patients

*Ohio Benefit Bank – OhioBenefits.org or 1 (800) 648.1176*

- + Free screenings and applications for several Ohio benefit programs

*Ohio Medicaid Consumer Hotline – 1 (800) 324.8680*

- + Information on Medicaid benefits, eligibility and application

*OhioHealth Financial Assistance – (614) 566.1505*

- + Assistance with OhioHealth expenses based on income eligibility

*OhioHealth Senior Health Insurance Information Program (OSHIIIP) – 1 (800) 686.1578*

- + Free health insurance information and services for Ohioans with Medicare

*Social Security Administration – SocialSecurity.gov or 1 (800) 772.1213*

- + Information on Social Security disability and Supplemental Security Income (SSI) benefits, eligibility and application.

### Community Resources in Your Area

*2-1-1 – 211.org or dial 211*

- + Free referral and information service linking individuals to resources in their communities, including emergency food, shelter, rent and utility assistance, and mental health services

*Columbus Cancer Clinic – (614) 263.5006*

- + Need-based program assisting with transportation, food and cancer-related medications for people in active treatment

*Ohio Area Agency on Aging – OhioAging.org or (614) 481.3511*

- + Services for seniors age 60 or above, including transportation and home-delivered meals
- + For services in Ashland, Crawford, Huron, Knox, Marion, Morrow, Richland, Seneca and Wyandot counties, call 1 (800) 860.5799. For services in Hardin county, call 1 (800) 653.7277.

### Transportation Needs

*American Cancer Society – Cancer.org or 1 (800) 227.2345*

- + Volunteer transportation (availability varies by county)

*Medicaid Transportation – Contact your insurance plan or local Job and Family Services office.*

- + Nonemergency medical transportation for Medicaid enrollees

*For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.*



## Help for Patients, Survivors, and Caregivers

The American Cancer Society offers support in your community and online to help you during and after cancer treatment. Visit [cancer.org](https://www.cancer.org) or call us at **1-800-227-2345** for more information.

### Free cancer information center

The American Cancer Society National Cancer Information Center offers help as you're dealing with cancer by connecting you to our caring, trained staff to answer questions about a diagnosis, identify resources, or provide a listening ear and guidance. We offer health insurance assistance, American Cancer Society programs, and referrals to other services. Call us at **1-800-227-2345** or visit [cancer.org](https://www.cancer.org) to live chat with us. We can assist in English, Spanish, and more than 200 other languages via a translation service.

### Printed materials about cancer

Our materials can help you and your loved ones understand your diagnosis, treatment, and potential side effects, and provide detailed information on our programs and services. Our printed materials are available for free when you contact us at **1-800-227-2345** or through your cancer care team.

### Places to stay during treatment

Our Hope Lodge® program provides a free, nurturing home away from home for cancer patients and their caregivers when they have to travel for treatment. In some areas where we don't have a Hope Lodge community or it is full, our Hotel Partners Program lets patients and caregivers stay for free or at reduced rates in hotels close to where they get treatment.

### Rides to treatment

One of the biggest roadblocks to timely quality cancer treatment is the lack of transportation. Family and friends may help, but over the course of several months,

they may not always have the time or resources to provide every ride. That's why the American Cancer Society started the Road To Recovery® program. It is at the very heart of our work of removing barriers to quality health care by providing patients transportation to treatment and other cancer-related appointments through volunteer drivers, partners, and community organizations.

### Patient navigation

Our patient navigators, available at many hospitals nationwide, help patients get the services they need so the rest of their cancer care team can focus on treatment. Patient navigators can also provide cancer and treatment information customized for each patient's diagnosis, help them find local resources to help make sure they get the treatment they need, and more.

### Cancer Survivors Network<sup>SM</sup>

Visit [csn.cancer.org](https://www.csn.cancer.org) to join our online community for people with cancer and their families. Find and connect with others in treatment, long-term survivors, or caregivers through our member search, discussion boards, chat rooms, and private Cancer Survivors Network email.

### Reach To Recovery®

The Reach To Recovery program matches breast cancer patients with trained volunteers who have had similar diagnoses and treatment plans to provide more personal, peer-to-peer support.

### “tlc” – Tender Loving Care®

Our “tlc” (Tender Loving Care) publication offers affordable hair loss and mastectomy products for women coping with cancer, as well as advice on how to use them. Products include wigs, hairpieces, hats, turbans, breast forms, mastectomy bras, mastectomy camisoles, and mastectomy swimwear. Call **1-800-850-9445**, or visit the “tlc”™ website at [tlcdirect.org](https://www.tlcdirect.org) to order products or catalogs.

### American Cancer Society books

We have more than 40 award-winning books on specific cancers, general cancer information, caregiving, coping with cancer and side effects, emotional support, books for families and children, and more. You can purchase American Cancer Society books and e-books at [cancer.org/bookstore](https://www.cancer.org/bookstore), or book retailers nationwide.

### Survivorship guidelines and resources

We have materials and resources for survivors to help with quality-of-life and other needs during and after cancer treatment. Our cancer survivorship guidelines for specific cancers help doctors manage the unique needs of survivors, and our nutrition and physical activity guidelines for survivors help you know how to live your best life and reduce your risk for cancer coming back.

### Springboard Beyond Cancer

This online tool for cancer survivors, created by the American Cancer Society and the National Cancer Institute, is available at [survivorship.cancer.gov](https://www.survivorship.cancer.gov). Patients and survivors can create personalized Action Decks, collections of selected information to help them better communicate with caregivers and their care teams to manage their physical and emotional care after a cancer diagnosis.

### For caregivers

Cancer affects both you and your loved ones. Our information for caregivers at [cancer.org/caregivers](https://www.cancer.org/caregivers) helps them care for you while also remembering their own needs and shows them how to ask for help and support. They can also visit [csn.cancer.org](https://www.csn.cancer.org) for caregiver forums.

### Clinical trials

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials or contact our National Cancer Information Center at **1-800-227-2345** and speak with one of our caring, trained staff.

### cancer.org

Our website offers access to the most recent and accurate cancer information and news and helps you find programs and services in your area. A few pages of note are:

- [cancer.org/survivors](https://www.cancer.org/survivors) – a hub for support and treatment topics, treatment and survivorship tools, and stories of hope to inspire you
- [cancer.org/videos](https://www.cancer.org/videos) – features to-the-point videos on cancer-related topics, including cancer basics, cancer treatments, clinical trials, American Cancer Society programs and services, the effects of survivorship, personal stories, and more
- [cancer.org/treatmentdecisions](https://www.cancer.org/treatmentdecisions) – cancer treatment decision tools and resources to help you get through cancer diagnosis and treatment
- [cancer.org/support](https://www.cancer.org/support) – more information about the American Cancer Society and other programs and services in your area
- [cancer.org/languages](https://www.cancer.org/languages) – links non-English speakers to cancer information in other commonly spoken languages
- **Live Chat** with our caring, trained staff simply by going to [cancer.org](https://www.cancer.org) and clicking on “Live Chat”



[cancer.org](https://www.cancer.org) | **1.800.227.2345**



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## Clinical Trials

According to national best practice, the best management of a cancer patient may include participation in a clinical trial (*National Comprehensive Cancer Network, 2016*).

Nearly all modern cancer treatment has developed as a result of clinical trials and research. This is how treatments that were once experimental become standards of care. There are many laws and processes in place to protect your rights and health. Thousands of people are helped each year because they decided to take part in a clinical trial (research study), and millions more benefit from their efforts.



Our physicians encourage all eligible cancer patients to participate in a clinical trial. These studies are designed to find answers to specific health questions. They often look at the benefits of new:

- + Cancer prevention methods.
- + Drugs or combinations of drugs.
- + Surgical procedures or devices.
- + Ways to use existing treatments, such as radiation therapy.
- + Way to help with the side effects of treatment.
- + Ways to improve quality of life.

OhioHealth participates in regional, national and international research networks. We also provide increased access to research through select clinical trials as a certified member of MD Anderson Cancer Network®, a program of MD Anderson Cancer Center. Our cancer research program offers the newest treatments and therapies, placing us at the forefront of cancer care.

## Who conducts clinical trials?

Clinical trials are carried out by a team of healthcare experts who connect you to the latest advances in cancer care. Each patient is assigned a clinical trial team member to guide them through treatment.

Key members include:

- + Your physician, who oversees your care and treatment throughout your study.
- + Your nurse or research coordinator, who helps manage your care, provides information about the study, assists you in managing any symptoms and collects information about how the treatment affects you.
- + You, the most vital and important part of the team. Your participation and cooperation will enable us to make advances in treatment that can be of great benefit for years to come.

## Who can participate in a clinical trial?

Your physician will evaluate your eligibility for clinical trials. A clinical trial may be an option for you in combination with your current treatment plan.

## What questions should I ask my physician if I am considering a clinical trial?

- + Is there a clinical trial that I may be eligible for?
- + What is the purpose of this clinical trial?
- + Has the treatment been used before?
- + Will I be able to receive the treatment after the study is over?
- + What is my financial responsibility?
- + Will there be added costs?

For more information about research at OhioHealth, contact the OhioHealth Research Institute at (614) 566.1250 or visit [OhioHealth.com/OHRI](http://OhioHealth.com/OHRI).



Supportive care is an important part of your health and well-being. At OhioHealth, we provide information, support and resources to meet your physical, spiritual and emotional needs throughout the continuum of care.

OhioHealth provides cancer patients with services, education and support from diagnosis through survivorship, including:

- + Advance care planning
- + Cancer rehabilitation
- + Cancer wellness
- + Fertility counseling
- + Integrative care
- + Patient navigation
- + Support groups
- + Survivorship support
- + Tobacco cessation

## Patient Navigation – Where Supportive Cancer Care Begins

One of the first people you'll be connected with at OhioHealth is a patient navigator — registered nurses and social workers who provide support, education and guidance for you and your family. Our patient navigators have one goal: to improve your care experience and quality of life through education, support, and facilitating your access to care.

Your patient navigator will:

- + Educate you and your family about your cancer and what to expect during and after treatment.
- + Assist with communication between you and your care team.
- + Coordinate care with your managing physicians and interdisciplinary team.

- + Connect you with resources that provide education, advocacy and emotional support.
- + Address questions and concerns specific to your type of cancer or treatment.
- + Connect you to resources for wigs, hats, scarves, clothing and prosthetic devices.

## Fertility Counseling

There are options available to help preserve fertility in men and women during cancer treatment. Even if you are unsure whether or not you want to have children, your physician can provide information about these options.

## Integrative Care

Integrative care focuses on healing the whole person, and can help improve your physical, mental and emotional well-being during and after cancer treatment. Complementary therapies, such as acupuncture, massage therapy, nutritional planning, wellness, mind-body therapies and counseling may be combined with your cancer care plan to help:

- + Manage symptoms, such as pain, nausea and fatigue.
- + Improve quality of life.
- + Enhance the effectiveness of your cancer treatment plan.

## Advance Care Planning

With advance care planning (living will and durable power of attorney for healthcare), you can make decisions based on your own preferences, values and beliefs about the healthcare you wish to receive if you become unable to represent yourself. Your family members and healthcare providers should be informed of your wishes. OhioHealth can help you put these preferences in writing. *Talk to your navigator or social worker if you have questions.*

## Cancer Rehabilitation

Our team of therapists will help you maintain and improve your quality of life during and after cancer treatment through education and traditional physical, occupational and speech therapy, in addition to treatment-related therapies, including lymphedema therapy and pelvic floor therapy.

## Survivorship Support

Your *Treatment Summary and Survivorship Care Plan* is a written summary of the care you received and guidelines for ongoing surveillance by your healthcare providers after you've completed treatment.

- + *Survivorship Clinics* help you and your family overcome challenges as you transition from active cancer treatment to survivorship. Our clinics focus on education, symptom management, cancer prevention and wellness to identify your issues and concerns related to the physical, mental, emotional and social effects of cancer treatment. During your visit, you will learn about:
  - Cancer screening recommendations.
  - Managing late and long-term side effects of cancer treatment.
  - Emotional and social effects of cancer treatment.
  - Information about healthy behaviors.
  - The role of genetic counseling in cancer survivorship.
- + *Weight Management for Cancer Survivors* is a program that helps survivors achieve and maintain a healthy weight, as both diet and activity play an important role in cancer survivorship. Our program gives you the tools and skills you need to manage your diet and modify your lifestyle by:
  - Tying education about nutrition and weight management to cancer risk.
  - Debunking myths about food and food additives, and their relationship to cancer.
  - Offering cancer-specific exercise tips.

## Over My Head Boutique

This unique boutique offers women a place to go to feel better and gain more confidence during a difficult time in their lives. From custom wigs to prosthetics and specialty skin care products, Over My Head can help women look and feel their best.



## Financial Support

A variety of financial assistance options are available to you throughout the course of your care, from screening through treatment and into survivorship. Talk to your patient navigator about financial support options.

### Ongoing Health and Wellness Programs

#### Tobacco Cessation

OhioHealth has certified tobacco treatment specialists available throughout the region to help you quit using tobacco. Our free six-week tobacco cessation course focuses on group support, education and motivation to remove the barriers to quitting tobacco.

#### Cancer Wellness

Combining good nutrition and emotional support with safe, effective exercise is essential to your recovery process. Physical activity reduces fatigue and stress, strengthens immune function, increases energy, muscle strength and endurance, reduces body fat and, in some cases, reduces the risk of recurrence. Our trained wellness coaches and exercise specialists will teach you the importance of safely exercising to give you more energy during treatment and how to exercise following treatment.

#### OhioHealth Cancer Walk/Run Club

The OhioHealth Cancer Walk/Run Club is a training program for anyone who is newly diagnosed, currently in cancer treatment or finished with cancer treatment that guides you toward running or walking a 5K race. While training, you receive online support through weekly emails, the opportunity to participate in live group workouts with other club members and OhioHealth associates, and access to health and wellness opportunities, such as educational presentations from expert physicians. The club's mission is to help you take charge of your recovery and wellness in a group setting that brings about hope and inspiration.

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.



# What is cancer?

## A guide for patients and families



## What is cancer?

Cancer can start any place in the body. It starts when cells grow out of control and crowd out normal cells. This makes it hard for the body to work the way it should. Cancer can be treated very well for many people. In fact, more people than ever before lead full lives after cancer treatment.

Here we will explain what cancer is and how it's treated. You'll find a list of words about cancer and what they mean at the end of this booklet.

## Cancer basics

### Cancer is not just one disease.

There are many types of cancer. It's not just one disease. Cancer can start in the lungs, the breast, the colon, or even in the blood. Cancers are alike in some ways, but they are different in the ways they grow and spread.

### How are cancers alike?

The cells in our bodies all have certain jobs to do. Normal cells divide in an orderly way. They die when they are worn out or damaged, and new cells take their place. Cancer is when the cells start to grow out of control. The cancer cells keep on growing and making new cells. They crowd out normal cells. This causes problems in the part of the body where the cancer started.

Cancer cells can also spread to other parts of the body. For instance, cancer cells in the lung can travel to the bones and grow there. When cancer cells spread, it's called metastasis (meh-TAS-tuh-sis). When lung cancer spreads to the bones, it's still called lung cancer. To doctors, the cancer cells in the bones look just like the ones from the lung. It's not called bone cancer unless it started in the bones.

### How are cancers different?

Some cancers grow and spread fast. Others grow more slowly. They also respond to treatment in different ways. Some types of cancer are best treated with surgery; others respond better to

drugs called chemotherapy (key-mo-THER-uh-pee). Often 2 or more treatments are used to get the best results.

When someone has cancer, the doctor will want to find out what kind of cancer it is. People with cancer need treatment that works for their type of cancer.

## What are tumors?

Most cancers form a lump called a tumor or a growth. But not all lumps are cancer. Doctors take out a piece of the lump and look at it to find out if it's cancer. Lumps that are not cancer are called benign (be-NINE). Lumps that are cancer are called malignant (muh-LIG-nunt).

There are some cancers, like leukemia (cancer of the blood), that don't form tumors. They grow in the blood cells or other cells of the body.

## What stage is the cancer?

The doctor also needs to know if and how far the cancer has spread from where it started. This is called the cancer stage. You may have heard other people say that their cancer was stage 1 or stage 2. Knowing the stage of the cancer helps the doctor decide what type of treatment is best.

For each type of cancer there are tests that can be done to figure out the stage of the cancer. As a rule, a lower stage (such as a stage 1 or 2) means that the cancer has not spread very much.

“

*There is a fear that goes through you when you're told you have cancer. It's so hard in the beginning to think about anything but your diagnosis. It's the first thing you think about every morning. I want people with cancer to know it does get better.*

*Talking about your cancer helps you deal with all of the new emotions you are feeling. Remember, it's normal to get upset.*

**Delores**  
cancer survivor



A higher number (such as a stage 3 or 4) means it has spread more. Stage 4 is the highest stage.

Ask your doctor to explain the stage of your cancer and what it means for you.

## How is cancer treated?

The most common treatments for cancer are surgery, chemotherapy, and radiation (ray-dee-A-shun).

Surgery can be used to take out the cancer. The doctor might also take out some or all of the body part the cancer affects. For breast cancer, part (or all) of the breast might be removed. For prostate cancer, the prostate gland might be taken out. Surgery is not used for all cancers. For example, blood cancers like leukemia are best treated with drugs.

Chemo (which is short for chemotherapy) is the use of drugs to kill cancer cells or slow their growth. Some chemo can be given by IV (into a vein through a needle), and others are a pill you swallow. Because chemo drugs travel to nearly all parts of the body, they are useful for cancer that has spread.

Radiation is also used to kill or slow the growth of cancer cells. It can be used alone or with surgery or chemo. Radiation treatment is like getting an x-ray. Sometimes it's given by putting a "seed" inside the cancer to give off the radiation.

## What treatment is best for me?

Your cancer treatment will depend on what's best for you. Some cancers respond better to surgery; others respond better to chemo or radiation. Knowing the type of cancer you have is the first step toward knowing which treatments will work best for you.

The stage of your cancer will also help the doctor decide on the best treatment for you. A stage 3 or 4 cancer is likely to respond better to treatments that treat the whole body, like chemo.

Your health and the treatment you prefer will also play a part in deciding about cancer treatment. Not all types of treatment will work for your cancer, so ask what options you have. And treatments do have side effects, so ask about what to expect with each treatment.

Don't be afraid to ask questions. It's your right to know what treatments are most likely to help and what their side effects may be.

“

*What was helpful for me was taking the time to step back and see the big picture. Getting the answers to my questions helped me to make a good decision. I did what I wanted and needed to do. I did things that made me feel comfortable, not what others thought I needed to do to be comfortable.*

**Kevin**  
cancer survivor



## Why did this happen to me?

People with cancer often ask, "What did I do wrong?" or "Why me?" Doctors don't know for sure what causes cancer. When doctors can't give a cause, people may come up with their own ideas about why it happened.

Some people think they're being punished for something they did or didn't do in the past. Most people wonder if they did something to cause the cancer.

If you're having these feelings, you're not alone. Thoughts and beliefs like this are common for people with cancer. You need to know that cancer is not a punishment for your past actions. Try to not blame yourself or focus on looking for ways you might have prevented cancer. Cancer is not your fault, and there's almost never a way to find out what caused it. Instead, focus on taking good care of yourself now.

Your American Cancer Society can tell you more about cancer and cancer treatment. Call **1-800-227-2345** anytime, day or night.

## How to talk to your loved ones about cancer

It can be hard to talk about cancer, even with the people you love. Learning you have cancer can stir many feelings, such as sadness, anger, and fear. Sometimes it's hard to know how you're feeling, much less talk to others about it.

Your loved ones may also have a hard time talking about cancer. It's not easy for them to know what to say to help you or make you feel better.

Here are some tips to help you and your loved ones deal with cancer:

- Tell your family and friends about your cancer as soon as you feel up to it. Sooner or later, they'll all know you have cancer. They might feel hurt or left out if they haven't heard about it from you.
- When you talk to them, explain what kind of cancer you have and how it will be treated. Let them know that no one can catch it from you.
- Allow friends and family to help you, and tell them what kind of help you need. If you need a ride to the doctor's office or hospital, let them know. If you need help around the house, let them know that, too. There may be times when you're not sure what you need. That's OK. Just let them know you aren't sure, but you'll let them know when you are.
- Tell the people who are closest to you how you feel. This may not be easy, but it can be a very important way to get the

“

*The first time you say, 'I have cancer' out loud is the hardest. The more you say it, the easier it becomes to say the words. The more I talked about my breast cancer, the easier it was for me to accept what I was going through. I found it odd that I sometimes had to cheer up those I was telling about my cancer.*

**Helen**  
cancer survivor



support you need when you need it most. If you have trouble talking about your feelings, you might find a support group or a mental health counselor to help you.

- If you have friends or family who tell you to “cheer up” when you're not feeling good, it's OK to ask them to just listen, and not tell you what to do. Sometimes you need to talk about what's going on without getting advice in return.
- If some people are not OK with talking about your feelings, don't be upset. Try talking to others who might listen.
- You may not be able to do things you were doing before you got cancer. If that's true, let your family and friends know.
- It's best for your family and friends to keep doing the things they did before you had cancer. They should not feel guilty about doing this.
- If you're feeling sad or depressed, talk to your doctor, nurse, or religious leader. You can also call the American Cancer Society at **1-800-227-2345**.

## Cancer words you may hear

These are words that you may hear your cancer care team use.

**Benign (be-NINE):** a tumor that's not cancer

**Biopsy (BY-op-see):** taking out a piece of tissue to see if cancer cells are in it

**Cancer (CAN-sur):** a word used to describe more than 100 diseases in which cells grow out of control; or a tumor with cancer in it

**Chemotherapy (key-mo-THER-uh-pee):** the use of drugs to treat disease. The word most often refers to drugs used to treat cancer. Sometimes it's just called "chemo."

**Malignant (muh-LIG-nunt):** having cancer in it

**Metastasis/Metastasized (meh-TAS-tuh-sis/ meh-TAS-tuh-sized):** the spread of cancer cells to distant parts of the body through the lymph system or bloodstream

**Oncologist (on-KAHL-uh-jist):** a doctor who treats people who have cancer

**Radiation therapy (ray-dee-A-shun THER-uh-pee):** the use of high-energy rays, like x-rays, to treat cancer

**Remission (re-MISH-un):** when signs or symptoms of cancer are all or partly gone

**Stage:** a word that tells whether a cancer has spread, and if so, how far

## How can I learn more about my cancer?

If you have questions about cancer or need help finding resources in your area, please call the American Cancer Society, at **1-800-227-2345** anytime, day or night. You can also visit our website, **[www.cancer.org](http://www.cancer.org)**, to learn more.



**This is a booklet about cancer. It tells you things like:**

- What cancer is
- What cancer stage is
- How cancer is treated
- How to decide about cancer treatment
- How you and your loved ones can help each other through this time

For cancer information, day-to-day help, and emotional support, call your American Cancer Society at **1-800-227-2345**. We're here when you need us – 24 hours a day, 7 days a week.



cancer.org | 1.800.227.2345  
1.866.228.4327 TTY



bbb.org/charity

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# Distress

SUPPORTIVE CARE BOOK SERIES

Presented with support from:



Available online at [NCCN.org/patients](http://NCCN.org/patients)

**EVERYONE** with cancer has some level of distress at some point in time.

The first goal of this book is to help you and your cancer care team talk about distress throughout your cancer journey. The second goal is to help you get relief from distress if needed.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world’s leading cancer centers. Experts from NCCN have written guidelines on distress management for cancer care teams and psychosocial professionals. These guidelines suggest the best practice for distress management. The information in this patient book is based on the guidelines written for health care workers.

This book focuses on distress management. Key points of the book are summarized in the related *NCCN Quick Guide™*. NCCN also offers patient resources on nausea and vomiting, adolescents and young adults with cancer, lung cancer screening, and treatment for many types of cancer. Visit [NCCN.org/patients](http://NCCN.org/patients) for the full library of patient books, summaries, and other resources.



These patient guides for cancer care are produced by the National Comprehensive Cancer Network® (NCCN®).

The mission of NCCN is to improve cancer care so people can live better lives. At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health care workers plan the best cancer care. They list options for cancer care that are most likely to have the best results. The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

Panels of experts create the NCCN Guidelines. Most of the experts are from NCCN Member Institutions. Their areas of expertise are diverse. Many panels also include a patient advocate. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit [NCCN.org/clinical.asp](http://NCCN.org/clinical.asp).

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NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from the world’s leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources. NCCN Foundation is also committed to advancing cancer treatment by funding the nation’s promising doctors at the center of cancer research, education, and progress of cancer therapies.

For more information about NCCN Foundation, visit [NCCNFoundation.org](http://NCCNFoundation.org).

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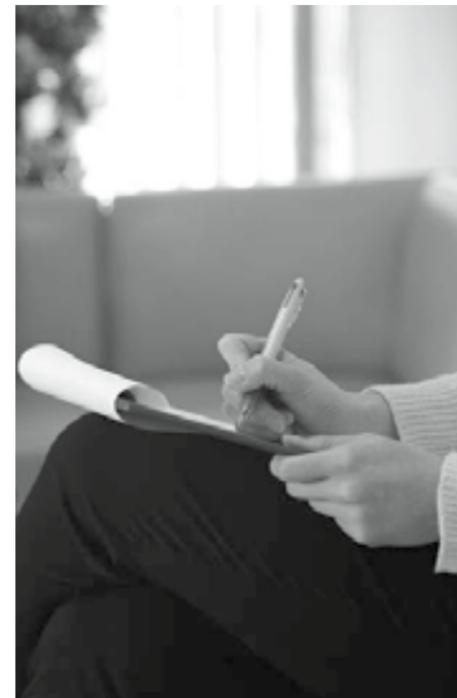
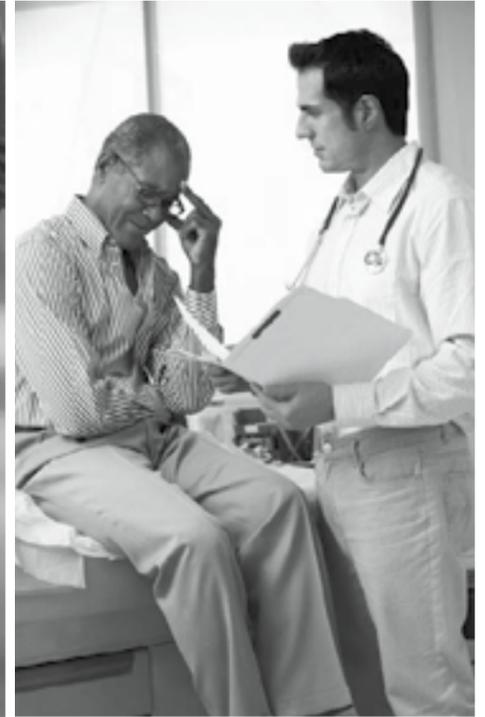
Good Days is proud to support this educational resource for patients and their families and offers unwavering commitment to those who struggle with chronic disease, cancer, and other life-altering conditions.

Good Days is a national, independent 501(c)(3) non-profit charitable organization that provides financial assistance to patients so that they do not have to choose between getting the treatment they need and affording the necessities of everyday living.  
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### American Psychosocial Oncology Society

American Psychosocial Oncology Society (APOS) is pleased to endorse the NCCN Guidelines for Distress. APOS stands behind early psychosocial distress screening and distress management of cancer patients as an integral part of comprehensive cancer care. Education about distress management for those affected by cancer and all who support them will prove most valuable throughout the cancer journey. The NCCN guidelines provide this resource in an easily navigated document. [apos-society.org](http://apos-society.org)



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What help is there?  
Explains the types of treatment for distress.
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### Who should read this book?

Distress is very common among people with cancer. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It may help you talk with your cancer care team about your distress and get help if needed.

### Where should you start reading?

**Part 1** is a good starting point to learn what distress is. In **Part 2**, the tools used to assess for distress are described, and in **Part 3**, the types of help for distress are described. **Part 4** provides information to help you talk with your health care providers and obtain help.

### Does the whole book apply to you?

This book includes information for many people. Your cancer care team can point out what parts of the book apply to you. They can also give you more information. As you read through this book, it may help to make a list of questions to ask your health care providers.

### Help! What do the words mean?

In this book, medical words are included. Some of these words may be new to you. Don't be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. Acronyms are also defined when first used and are in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is CBT for **c**ognitive **b**ehavioral **t**herapy.

# 1

## What is distress?

8 Distress defined

9 Outcomes

10 Causes and risks

10 Triggers

12 Review



### 1 What is distress?

### Distress defined

Part 1 explains the basics about distress. You can learn what distress is and how it may affect your life. Part 1 also describes who may have higher levels of distress. Likewise, the time points at which distress is more likely are listed.

#### Distress defined

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Distress occurs across a range of experience. It can be mild and consist of common feelings like sadness, fear, and helplessness. On the other hand, it can be more severe. Higher levels of distress can cause problems in one or more areas of life. You may struggle with taking care of yourself, your social life, emotions, faith, and so forth.

Everyone with cancer has some distress at some point in time. It is normal to feel sad, fearful, and helpless. You are not “crazy” if you are distressed. Distress is expected.

There are many symptoms of distress. See Guide 1. The type and number of symptoms differ between people. Certain symptoms can be caused by things other than distress. Thus, it is important to tell your treatment team if you have any of these symptoms. Tips for talking with your cancer care team are given in Part 4.

#### Guide 1. Symptoms of distress

##### Some symptoms of distress are:

- Sadness, fear, and helplessness
- Anger, feeling out of control
- Questioning your faith, your purpose, the meaning of life
- Pulling away from too many people
- Concerns about illness
- Concerns about your social role (ie, as mother, father, caregiver)
- Poor sleep, appetite, or concentration
- Depression, anxiety, panic
- Frequent thoughts of illness and death

## Outcomes

Distress is linked with a number of negative factors. This section describes some of the outcomes of distress and other factors that are linked to distress. These negative factors are some of the reasons why distress screening and treatment are so important.

### **By definition, being distressed isn't pleasant.**

Feeling lousy doesn't make coping with cancer any easier. You have enough on your plate learning about cancer, going through treatment or follow-up care, and doing your everyday duties.

**Distress may affect how well you function.** It can interfere with sleep. You might sleep less or more than normal. Distress may affect how well you can focus. You may need to ask people to repeat what they said because you lost track. Distress may affect how well you relate to people. You may pull away from others. If you have children, you may have trouble taking care of them.

**Distress may interfere with your health decisions or actions.** Research found that people who are distressed are less likely to take their medicines as their doctor prescribed. Likewise, distressed people are less likely to attend their follow-up visits. As a result, you may make extra visits to the doctor's office and emergency room. If you're distressed, you may also have trouble making treatment decisions and be less likely to exercise and quit smoking.

**Distress may worsen your health.** Distress leads to poorer quality of life. It may even have a harmful impact on your length of life (survival). Keep reading this book to learn about distress screening and getting help.



*It's hard to deal with all of the things that happen at once, and not to just collapse and worry and stress.*

–Pauline

Wife of a Cancer Survivor



## Causes and risks

There isn't one cause of distress. What causes distress for one person with cancer may not be the same for another person. For example, people who are distressed may feel overwhelmed. Some have many side effects from treatment. Others struggle with worries or have money problems. Even if you have been wise with your money, the costs related to cancer can add up.

Anyone can become distressed but research has found that some people are more likely than others. The risk factors for higher levels of distress are listed in [Guide 2](#). A risk factor is anything that increases the chance of an event. There is a wide range of risk factors for distress.

You may have health-related risk factors. Some people have symptoms from the cancer, from the cancer treatment, or both. If your symptoms are severe or long lasting, your chance of becoming distressed is increased. Having another severe illness, cognitive impairment, or limited access to health care can also lead to distress.

You may have personal risk factors. Such factors include being young, being a woman, and having problems with communication. It may be a shock to learn that you have cancer. Likewise, it may be too much to deal with cancer and your everyday duties. Your chance for becoming distressed is also increased if you don't know the words your treatment team uses or you don't have access to information.

Money may get even tighter. You may have less money due to travel costs, insurance co-payments, and missing work. With less money, your chance of becoming distressed is increased.

Spiritual and social factors can contribute to distress. You may have long-standing or new spiritual or religious concerns in the context of having cancer.

Family conflicts, a lack of family support, and living alone may increase the burden of having cancer and lead to distress. Having young children is an important responsibility. Raising children and dealing with cancer at the same time can be very hard to do.

Higher levels of distress are linked to sexual and physical abuse, substance use disorders (ie, alcohol, drugs), and other mental disorders. If you have been abused, you are more likely to become distressed at some point during your cancer care. If you have had a mental or substance use disorder, your chance of being distressed is higher than someone who has not.

## Triggers

Distress can occur at any point in time during your cancer journey. However, there are times when being distressed is more likely. Read [Guide 3](#) for a list of times of when you are more likely to be distressed.

Distress may result from learning you have cancer. It may also occur beforehand when being assessed for cancer. Transitions in care can also lead to distress. Examples of a transition include being discharged from the hospital or finishing all treatment. It can be a big change when shifting from frequent doctor visits during active treatment to less frequent visits during follow-up care. Another common time point for being distressed is learning that your health has worsened.

Ideally, you would be screened for distress at every health care visit. However, it is very important that you be assessed for distress at the time points listed in [Guide 3](#). Screening tools for distress are described in [Part 2](#) along with some of the benefits of distress screening.

Guide 2. Risk factors for higher distress

You are more likely to be distressed if you:	
• Have uncontrolled symptoms	• Have spiritual or religious concerns
• Have a severe illness other than cancer	• Have family conflicts
• Have cognitive impairment	• Have a lack of social support
• Have limited access to health care	• Live alone
• Are younger in age	• Have young children
• Are a woman	• Have been physically or sexually abused
• Have barriers to communicating	• Have had a substance use disorder (ie, alcohol, drugs)
• Have money problems	• Have had a mental disorder (eg, anxiety, depression)

Guide 3. Vulnerable periods for distress

You are more likely to become distressed if you:	
• Learn a symptom needs more testing	• Were just admitted to or discharged from the hospital
• Are being assessed for cancer	• Recently finished treatment
• Just learned the diagnosis	• Are in follow-up care
• Are undergoing genetic testing	• Learn treatment didn't work
• Are waiting for treatment	• Learn the cancer has returned or progressed
• Are starting another type of treatment	• Have advanced cancer
• Have a major treatment-related complication	• Are near to the end of life

Review

- Distress is an unpleasant experience of a mental, physical, social, or spiritual nature.
- Everyone with cancer has some level of distress at some point in time.
- Distress may limit how well you function, interfere with your health decisions and self-care, and worsen your health.
- You may be more likely to be distressed than other people. Having uncontrolled symptoms, money problems, a lack of support, and other factors increases the likelihood for being distressed.
- There will be times during your cancer journey when being distressed is more likely. A change in your health, treatment, or health providers may lead to distress.



I worried how we would survive this financially.

-Carol  
Survivor, Multiple Myeloma

# 2

## How distressed are you?

14	Screening tools
14	Screening benefits
18	Role of cancer team
19	Experts in distress
21	Review



Assessing distress is a key part of cancer care. Part 2 is a review of the screening process for distress. Screening tools are described and the benefits of screening are explained. You can also learn who can help you with reducing distress.

### Screening tools

A screening tool is a short assessment for a condition. For distress, screening tools prompt you to respond to one or more verbal statements or questions. Distress screening tools have been tested in research studies. They have been found to work well for detecting who is distressed and pinpointing people's psychosocial needs.

There is more than one screening tool for distress. Screening tools are often paper-based surveys. However, hand-held devices, interactive voice responses, and internet-based programs have also been used. The screening tools created by NCCN experts in distress are described next.

#### The Distress Thermometer and Problem List

The Distress Thermometer is a well-known screening tool among cancer care providers. It has been shown in many studies to work well. It measures distress on a 0 to 10 scale. See page 16. To report your distress, circle the number that matches your level of distress in the past week.

The Problem List is completed along with the Distress Thermometer. It will help your cancer care team learn what is causing your distress. In turn, your team can ask better follow-up questions and refer you to the right help if needed.

You may receive a screening tool for distress at your next doctor's visit. You may complete the screen

while in the waiting room. If you are not screened for distress, share this book and your scores with your cancer care team.

Your cancer care team will discuss your scores with you. Some types of distress may be managed by your cancer care team. Other types may be better addressed by people with a different set of knowledge and skills. The experts in distress are described later in this chapter.

### Screening benefits

Distress screening is usually a quick process. If paired with getting help as needed, it can yield major benefits. Some of the benefits of distress screening are listed next.

**Detects who is distressed.** Without standard screening, less than half of distressed people are identified and get the help they need. Often, doctors don't ask and patients don't tell their doctors about their distress. Screening tools empower doctors to inquire about distress and empower patients to share how they are feeling. Read Part 4 to learn about distress screening becoming a standard of care for people with cancer.

**Detailed evaluations.** You may receive an in-depth assessment depending on what is bothering you. An example is memory testing if you say your memory is a big problem. Another example is a clinical assessment for high distress about sexual problems or pain. A clinical assessment may consist of one or more of the following: an interview, survey, or health tests.

**Better distress management.** Early distress screening leads to timely management of distress. A study of routine screening showed that distressed people referred to help as needed were less

distressed 3 months later. Better management of distress in turn improves self-care and health outcomes.

**Improved self-care.** Treating distress makes it easier to stay on track with your cancer treatment. You will be less likely to miss doctor's visits and skip taking your medicines. In turn, you won't feel the need to call and visit your doctor more often. Furthermore, it is easier to communicate with your treatment team when not distressed.

**Improved health outcomes.** Treating distress early helps to prevent emotional problems from becoming severe. You likely won't be angry all the time or be intensely angry. Severe anxiety and depression may also be avoided. In addition to mental health, treating distress may help your physical health. One study suggests that decreasing distress may lead to better survival for people with cancer.



You just can't imagine how much fear and anxiety builds up.

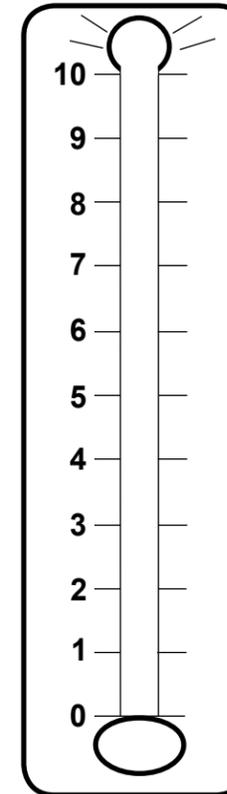
-Dan  
Survivor, Non-Small Cell Lung  
Cancer



### 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 Practical Problems**

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

**Family Problems**

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

**Emotional Problems**

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

- Spiritual/religious concerns**

**YES NO Physical Problems**

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

**Other Problems:**

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**Role of cancer team**

Learning that you have cancer and all the events that follow is a difficult time. Distress is a normal reaction and is to be expected. Distress screening tools can be used by your cancer care team to make a plan to meet your needs.

Your cancer care team can monitor your distress level. They can screen you for distress at future visits. They can also alert you of times when being distressed is more likely.

Your cancer care team can help to reduce your distress. Your team can manage expected distress symptoms, such as:

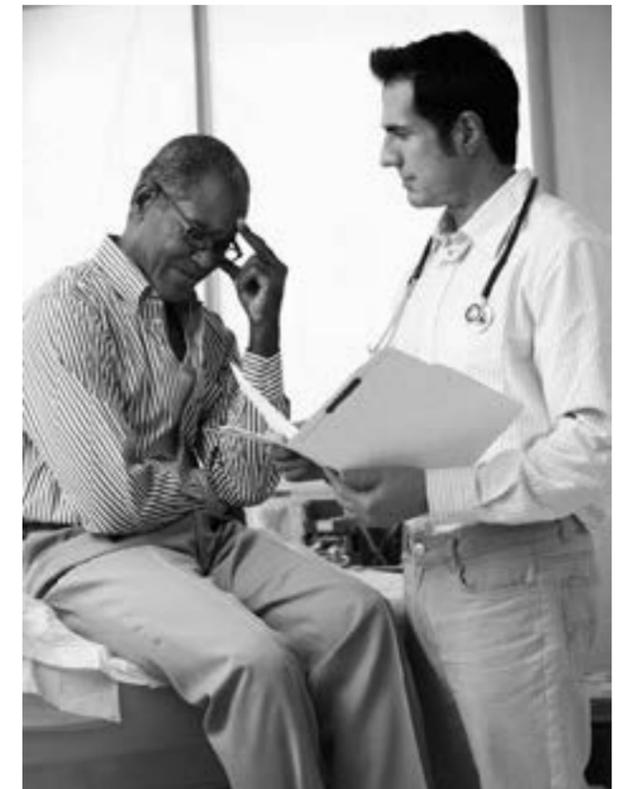
- Fear, worry, and uncertainty about the future,
- Concerns about cancer,
- Sadness about loss of health,
- Poor sleep, appetite, and concentration,
- Frequent thoughts of illness, treatment, side effects, or death; and
- Concerns about social roles (eg, mother, father, caregiver).

Your team can help by giving you information on cancer. They can also help by preventing gaps in care between health care providers. Some cancer centers have patient navigators that will guide you through the health care system. Another way your cancer team can help is to tell you about resources in your cancer center and community. They may refer you to an expert in distress.



On a daily basis I come across patients who are being absolutely drained of the resources they need.

-Dr. Fahd  
Oncologist





**Nurses**

The field of nursing greatly varies. The nurse on your cancer care team is likely an RN (registered nurse). RNs have earned at least an associate's degree or a diploma from a hospital-based program. All RNs are licensed to practice.

Some RNs go on to earn a master's or doctoral degree in nursing. They can also obtain certification to become an expert in certain areas. Examples of certification include oncology and psychiatry.

You may receive care from an NP (nurse practitioner). An NP has earned at least a master's degree in nursing, is licensed, and has passed a national certification exam. NPs provide more comprehensive care than RNs. In some states, they can prescribe medicines.

Nurses are often the first to detect that a person is distressed. They may be the one to screen you for distress. They will also inform your cancer care team of your state.

Nurses also provide a range of services for distress treatment. They can help with practical matters, provide counseling, and refer you to other experts.

**Review**

- A screening tool for distress is a brief survey of your perceived distress. The Distress Thermometer and Problem List were created by NCCN experts to assess the level and nature of your distress.
- Distress screening that is paired with help for related problems can be very helpful.

- Your cancer care team can assess you for distress at future visits and provide help for mild distress.
- Experts in distress have obtained education, training, and credentials to conduct evaluations and provide treatment. Depending on your needs, you may be referred to a chaplain, social worker, psychologist, psychiatrist, psychiatric nurse, or other mental health professional.

“

Cancer and my health situation have given me a new perspective. For one thing, I don't take any day for granted.

-Leonard

Survivor, Multiple Myeloma

## 3

**What help is there?**

23	Cancer education
23	Chaplaincy care
24	Social work and counseling
25	Mental health services
27	Review



The cause of distress greatly differs across people. In turn, the help for distress varies based on need. Part 3 is an overview of the common types of help for distress among people with cancer.

## Cancer education

Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. This information is important, as you will be deciding a treatment plan with your doctor. After treatment, you may have more doctor's visits and tests for a long time.

Learning about cancer and its treatment may reduce your distress. During your cancer journey, your cancer care team will likely use many medical words. Most of these words may be new to you, and it may seem like a lot to learn. Don't be shy to ask your team to explain a word or phrase that you do not understand.

There are many resources to help you learn about cancer. Your cancer center may have an information center that can provide information. Some cancer centers have a patient navigator program. Patient navigators sometimes help people learn more about cancer.

NCCN has a growing library of patient resources. This library includes the NCCN Guidelines for Patients® and the NCCN Quick Guide™. These resources are a good starting point from which to learn the best options for cancer care. Your cancer care team can provide more information to help you make treatment decisions. Visit [NCCN.org/patients](http://NCCN.org/patients) for resources on cancer screening, cancer treatment, and supportive care.

## Chaplaincy care

Spirituality or religion is important to many people. People use spiritual and religious resources to cope with cancer. Furthermore, there is a link between health and spirituality and religion. Data from multiple studies showed that spirituality and religion are related to better mental health. Also, attending religious services was related to fewer deaths from any cause including cancer.

Many people with cancer have spiritual needs. A chaplain can help you whether you have strong beliefs, different beliefs, conflicted beliefs, or no beliefs. Chaplains provide help for grief, guilt, and hopelessness. They can also address concerns about treatment, death, the afterlife, the Divine, and the meaning and purpose of life. You may want a chaplain to help you talk with your religious community, family, or treatment team.

Chaplains provide a range of services. They provide spiritual counseling. Your chaplain will listen to your concerns and provide advice and guidance as needed. You may receive more guidance or comfort through reading. Your chaplain may suggest a good reading resource to you.

Many people say prayer is a major help with dealing with cancer. Your chaplain can pray with you and pray on your behalf. Likewise, he or she can help get your ritual needs met. Your chaplain may be able to perform a ritual such as communion (Eucharist). If not, he or she can contact clergy of your faith.

Chaplains can serve as a contact between you and others. If you want, your chaplain can help you talk with your faith community. If you are not a member somewhere, your chaplain can help you connect with a local community.

## Social work and counseling

This section describes services for practical or psychosocial problems. Social workers are the main providers of these services. However, patient navigators provide help for certain practical problems at some cancer centers. The mental health services described in the next section may also be of help for practical or psychosocial problems.

### Practical problems

As described in Part 2, practical problems may relate to illness, food, money, work, school, language, and caregiving. Education, support groups, and a resource list may be enough help for mild problems. Read Part 4 for a list of online resources. At support groups, you will hear about the experiences of other people with cancer. You may learn some new ways to deal with practical problems.

For complex practical problems, education may be very helpful to you and your family. You may also benefit from learning problem-solving skills and receiving counseling. In addition, your social worker may take a very active role in linking you with community resources and be your advocate. He or she can help you obtain the support you need from other organizations.

### Psychosocial problems

Psychosocial problems include a wide range of issues. You may have trouble adjusting to being sick or with making decisions. Cancer may worsen your quality of life or cause unwanted changes to your body. Having cancer may also force the need to get an advance directive and deal with end-of-life issues. Psychosocial problems can also involve conflicts within your family or with others.

You and your family may find it helpful to learn more about the problem you are dealing with. Your social worker may have information for you or may refer you to an educational group. Likewise, counseling

and support groups that provide guidance may be of help. Counseling may focus on a specific topic like sex or grief. Like practical problems, help for psychosocial problems may come from community resources. For complex psychosocial problems, your social worker may refer you for chaplaincy care or mental health services.



Initially you're doing everything you can to survive and you can kind of get used to that and you're constantly fighting and then after a while, you get a chance to pop your head above water for a little bit, and look around, and you see all the people who are trying to throw you flotation, trying to help you keep your head above water and not sink and yelling out words of encouragement to you – and so ... you keep going.

–Steve

Brother of a Cancer Survivor

## Mental health services

Your cancer care team may refer you to a mental health professional. There are many types of mental health professionals. Examples include clinical social workers, psychologists, advanced practice clinicians, psychiatric nurses, and psychiatrists. The work of these professionals overlap but their expertise varies. Your cancer care team will refer you to someone who is a good fit.

The first step of care is often an evaluation to assess the problem. Evaluations differ between people based on the type of distress. Evaluations can consist of one or more of the following: interviews, surveys, and testing.

Based on the evaluation, your provider will make a treatment plan for you. Research has shown that mental health treatment works well to reduce distress and improve quality of life among people with cancer. The common types of mental health treatment are described next.

### Psychoeducation

Psychoeducation is a learning event for people with specific types of distress or health conditions. The focus of the event may be general, such as on stress management. Other events may have a specific focus, such as sun protection for people with melanoma.

There are many methods to deliver psychoeducation. One method is one-to-one teaching. Group psychoeducation is also common. Besides in-person learning, you may receive reading materials, DVDs, and online resources.

### Medicine

Some people need eyeglasses to function better. Likewise, some people need medicines to function better. Psychiatric (or psychotropic) medicines are drugs that improve mental health. These medicines



work by changing the amount of certain chemicals in the brain. Psychiatric medicines can be prescribed by psychiatrists, nurse practitioners, oncologists, and in some states, psychologists.

There are different types of psychiatric medicine. They are grouped by how they are commonly used. However, be aware that some medicines have other uses. An example is an antidepressant that can also help some women with hot flashes. The common classes of psychiatric medicines are listed next.

**Antidepressants.** These medicines treat depression. Two key features of depression are feeling down or irritable and losing interest in things that you used to like. Depression that is present at cancer diagnosis or during treatment may last a long time. There is strong proof that antidepressants work well to treat depression.

Antidepressants may be used with psychotherapy to treat depression. Antidepressants also treat anxiety and certain physical problems. Such physical problems include nausea, hot flashes, pain, and sleep problems. Read *Anxiolytics* to learn more about anxiety.

**Anxiolytics.** These medicines may be used with psychotherapy to treat anxiety. They are also called anti-anxiety medicines. Key features of anxiety

include severe fear or worry, panic attacks, and strong behavioral impulses. Anxiolytics are also helpful for anxiety related to stress or trauma.

**Mood stabilizers.** These medicines treat bipolar-related disorders. The key feature of bipolar disorders is an episode of elevated mood called mania. There is strong proof that mood stabilizers work well to treat mania.

**Psychostimulants.** These medicines help with alertness, attention, and energy. They treat attention deficit hyperactivity disorder and improve fatigue. Fatigue is an extreme tiredness despite getting enough sleep. A drug named methylphenidate seems to help cancer-related fatigue but more research is needed.

**Antipsychotics.** These medicines treat psychotic disorders. Features of psychotic disorders include perceiving unreal sensations (hallucinations), fixed false beliefs (delusions), and disorganized thinking (thought disorders). The stress of having cancer can trigger or worsen psychotic features. Some types of cancer or treatment can also cause or worsen psychosis.

Antipsychotics treat other health conditions, too. Your health provider may advise an antipsychotic for anxiety if other medicines did not work. Antipsychotics also treat delirium. Delirium is a short-term disturbance in mental abilities. It occurs in about 43 out of every 100 persons with advanced cancer. Some types of medicines that help people with cancer cause the delirium.

### Psychotherapy

Psychotherapy is a treatment for distress. It is also known as “talk therapy.” Despite this name, only a professional trained in specific methods can provide psychotherapy. Psychotherapy is provided one-on-one between patient and provider or in a group setting with other patients.



I was overwhelmed with anxiety about my future. Imagine if you have to work to maintain yourself, plus you have extreme fatigue and then the side effects of the medication, it's very difficult to cope.

—Gwen

Survivor, Non-Small Cell Lung Cancer

There are different types of psychotherapy. CBT (cognitive behavioral therapy) focuses on changing thoughts and actions that contribute to poor mental health. It can help with depression, anxiety, pain, and fatigue among people with cancer.

Supportive psychotherapy uses a flexible approach to meet people's changing needs. It is widely used to help people with cancer. Subtypes of this psychotherapy include supportive-expressive, cognitive-existential, and meaning-centered psychotherapy.

Cancer affects the whole family. Any family member can experience distress. Individual counseling may help. However, family and couples therapy may reduce distress better than treatment for one person. Some research has been done but more is needed to learn how well family and couples therapy works for families affected by cancer.

### Substance use disorder treatment

The word “substance” refers to alcohol, drugs, or tobacco. Disorders of these substances are defined by repeated use that causes major life problems.

Your chances for a substance use disorder are very low if you haven't had a problem before. Poor control of cancer-related symptoms may increase your chances of developing a substance problem.

You should have a thorough evaluation if you have had substance use disorder. Current use of some substances may require detox. After detox, specialized treatment programs to help you stay clean or sober are advised. If you haven't had a recent problem, be aware that relapse may occur under the stress of cancer. Joining a risk reduction program may be a good option.

### Complementary and integrative therapies

Complementary therapies are non-standard treatments given with standard treatments. An example is yoga given with psychotherapy. Some people call complementary therapies by a different name—integrative therapies. Others refer to the practice of providing both complementary and standard treatments as integrative therapy (or integrative medicine).

There is proof that complementary therapies improve mental health among people with cancer. One study reviewed 203 clinical trials. The study found that meditation, yoga, relaxation with imagery, massage, and music therapy might be helpful for depression among women with breast cancer. Music therapy, meditation, and yoga may also reduce anxiety.

### Exercise

Some people know that exercise can improve health among people with cancer. Fewer people know that exercise may also improve quality of life and mental health. More research is needed to learn how well exercise treats mental health among people with cancer.

## Review

- Learning more about cancer may reduce distress.
- A chaplain can meet your spiritual needs through counseling, prayer, and other services.
- Practical problems in life may be solved by learning new information or skills, counseling, attending support groups, and connecting with community resources.
- Psychosocial problems may be relieved by new information, counseling and supportive groups, and community assistance.
- Mental health services for distress are based on an evaluation. Psychoeducation may be helpful for some people while others greatly benefit from medication, psychotherapy, or both. People struggling with drugs, alcohol, or tobacco problems need substance treatment. Complementary therapy and exercise appear to improve mood and reduce anxiety.

# 4

## Have you received help?

29 It's a standard of care

30 Questions to ask

34 Websites

35 Review



Every distressed person with cancer should receive help. Part 4 gives a history of how distress management has become a standard of cancer care. It also provides a list of questions and websites for you to use.

This history is important to know. You should expect to receive distress screening and help at your cancer care visits. If your distress isn't addressed, ask for help.



Hope is a huge part of the cancer process because if you lose that, you don't have the inner strength you need to fight.

-Kris  
Survivor, Multiple Myeloma

### It's a standard of care

Everyone with cancer has some distress at some point in time. However, distressed people with cancer have been underserved for decades. In 1997, NCCN made a groundbreaking step by forming a panel to develop treatment guidelines for distress. The first guidelines for distress were completed in 1999. This book is based on the most current version of the guidelines.

The IOM (Institute of Medicine) is a nonprofit group that provides advice to the nation. Its aim is to help people make good health decisions. IOM is greatly respected among health care professionals.

In 2007, IOM released a report called *Cancer Care for the Whole Patient*. In this report, a treatment model for distress was proposed. The model is based on the work of the NCCN panel. It includes routine distress screening, treatment planning, referrals to experts in distress, and re-evaluation. The IOM report made distress management a new standard of quality cancer care.

The Commission on Cancer is a program of the American College of Surgeons. It grants accreditation to cancer centers that apply and meet their standards of quality cancer care. In 2015, new standards went into effect for cancer centers. These new standards included distress screening.

### Questions to ask

Ask your health care providers questions about distress. Being informed will help you make decisions. The questions below are in regard to the care you read about in this book. Feel free to use them or ask your own questions.

It may help to prepare questions before your visit. At the visit, repeat the answers given to you to confirm what you heard. You can also take notes and record your visit so you can later review what was said. Many people bring their spouse, partner, friend, or other family member for support.

### Distress

1. Is my symptom(s) part of being distressed?
2. Will my distress just go away in time?
3. How can you help me?
4. How can I help myself?
5. What help will my insurance cover?

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### Cancer information

1. What type of cancer do I have? Will it grow fast?
2. What tests do I need? How often are these tests wrong?
3. What options do I have? What will happen if I do nothing?
4. What are the pros and cons of each option? What are the side effects of treatment? What does each option require of me in terms of travel, time off, costs, and so forth?
5. What can be done to prevent or relieve side effects?
6. What are my chances that the cancer will return?
7. Are you board certified? If yes, in what area? How many people like me have you treated?

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### Spiritual care

1. What do chaplains do?
2. Are chaplains ministers or priests?
3. Can a chaplain help me if we're not of the same faith or if I have no faith?
4. Can a chaplain help other family members?

### Social work and counseling

1. What do social workers do?
2. Can you help me find a local support group?
3. Is there help for the high costs of cancer care?
4. Can you show me how to talk with my children, family, and friends?
5. How do I deal with people who are treating me differently?
6. How can counseling help with intimacy?
7. Can you help me get an advance directive?



## Review

- Distress management is a new standard of quality cancer care. Expect and ask for help from your cancer care team.
- Ask your health care providers questions about distress. Being informed will help you make decisions.
- There are community resources that can help. Many of these resources can be found online.



I talk with people every day who are in a place of despair. When they call us, they've usually just experienced a one-two punch. First, they've been told they have cancer. Second, after receiving encouraging news that there is medication that can potentially save their lives, they are devastated to discover the out-of-pocket cost of the medication is beyond their financial means, because insurance won't pay the full amount.

-Fran

Patient Care Specialist

# Glossary

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37 Dictionary

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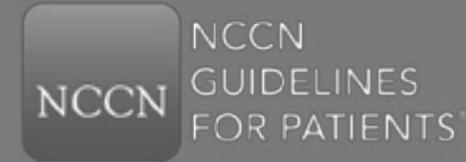
37 Acronyms

# Dictionary

- chaplain**  
A trained expert in providing spiritual care.
- cognitive impairment**  
Trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.
- diagnosis**  
To identify a disease.
- distress**  
Distress is an unpleasant experience of a mental, physical, social, or spiritual nature.
- oncologist**  
A medical doctor who's an expert in the treatment of cancer.
- psychiatrist**  
A medical doctor who's an expert in mental health.
- psychologist**  
A trained expert in the human mind and behavior.
- risk factor**  
Anything that increases the chance of an event.
- screening tool**  
A short assessment for a condition.
- side effect**  
An unplanned physical or emotional response to treatment.
- social worker**  
An expert in meeting people's social and emotional needs.
- substance use disorder**  
Repeated use of alcohol, drugs, or tobacco that causes major life problems.

# Acronyms

- CBT**  
Cognitive behavioral therapy
- IOM**  
Institute of Medicine
- NCCN®**  
National Comprehensive Cancer Network®
- NP**  
Nurse practitioner
- RN**  
Registered nurse



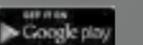
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# NCCN Member Institutions

**Fred & Pamela Buffett Cancer Center**  
Omaha, Nebraska  
800.999.5465  
[nebraskamed.com/cancer](http://nebraskamed.com/cancer)

**Case Comprehensive Cancer Center/ University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute**  
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[uhhospitals.org/seidman](http://uhhospitals.org/seidman)  
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[my.clevelandclinic.org/services/cancer](http://my.clevelandclinic.org/services/cancer)  
216.844.8797 • Case CCC  
[case.edu/cancer](http://case.edu/cancer)

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[cityofhope.org](http://cityofhope.org)

**Dana-Farber/Brigham and Women's Cancer Center Massachusetts General Hospital Cancer Center**  
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[dfbwcc.org](http://dfbwcc.org)  
[massgeneral.org/cancer](http://massgeneral.org/cancer)

**Duke Cancer Institute**  
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888.275.3853  
[dukecancerinstitute.org](http://dukecancerinstitute.org)

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[foxchase.org](http://foxchase.org)

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904.953.0853 • Florida  
507.538.3270 • Minnesota  
[mayoclinic.org/departments-centers/mayo-clinic-cancer-center](http://mayoclinic.org/departments-centers/mayo-clinic-cancer-center)

**Memorial Sloan Kettering Cancer Center**  
New York, New York  
800.525.2225  
[mskcc.org](http://mskcc.org)

**Moffitt Cancer Center**  
Tampa, Florida  
800.456.3434  
[moffitt.org](http://moffitt.org)

**The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute**  
Columbus, Ohio  
800.293.5066  
[cancer.osu.edu](http://cancer.osu.edu)

**Roswell Park Cancer Institute**  
Buffalo, New York  
877.275.7724  
[roswellpark.org](http://roswellpark.org)

**Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine**  
St. Louis, Missouri  
800.600.3606  
[siteman.wustl.edu](http://siteman.wustl.edu)

**St. Jude Children's Research Hospital The University of Tennessee Health Science Center**  
Memphis, Tennessee  
888.226.4343 • [stjude.org](http://stjude.org)  
901.683.0055 • [westclinic.com](http://westclinic.com)

**Stanford Cancer Institute**  
Stanford, California  
877.668.7535  
[cancer.stanford.edu](http://cancer.stanford.edu)

**University of Alabama at Birmingham Comprehensive Cancer Center**  
Birmingham, Alabama  
800.822.0933  
[www3.ccc.uab.edu](http://www3.ccc.uab.edu)

**UC San Diego Moores Cancer Center**  
La Jolla, California  
858.657.7000  
[cancer.ucsd.edu](http://cancer.ucsd.edu)

**UCSF Helen Diller Family Comprehensive Cancer Center**  
San Francisco, California  
800.689.8273  
[cancer.ucsf.edu](http://cancer.ucsf.edu)

**University of Colorado Cancer Center**  
Aurora, Colorado  
720.848.0300  
[coloradocancercenter.org](http://coloradocancercenter.org)

**University of Michigan Comprehensive Cancer Center**  
Ann Arbor, Michigan  
800.865.1125  
[mcancer.org](http://mcancer.org)

**The University of Texas MD Anderson Cancer Center**  
Houston, Texas  
800.392.1611  
[mdanderson.org](http://mdanderson.org)

**Vanderbilt-Ingram Cancer Center**  
Nashville, Tennessee  
800.811.8480  
[vicc.org](http://vicc.org)

**University of Wisconsin Carbone Cancer Center**  
Madison, Wisconsin  
608.265.1700  
[uwhealth.org/cancer](http://uwhealth.org/cancer)

**Yale Cancer Center/ Smilow Cancer Hospital**  
New Haven, Connecticut  
855.4.SMILOW  
[yalecancercenter.org](http://yalecancercenter.org)



## Questions to Ask My Doctor About My Cancer

Being told you have cancer can be scary and stressful. You probably have a lot of questions and concerns. Learning about the disease, how it's treated, and how this information might apply to you is a lot to do on your own. You might need some help. Your American Cancer Society can give you general information about the cancer and its treatment, but your doctor is the best source of information about your situation.

It's important for you to be able to talk frankly and openly with your cancer care team. They want to answer all of your questions, no matter how minor they might seem to you. But it helps if you know what to ask. Here are some questions you can use to help you better understand your cancer and your options. Don't be afraid to take notes and tell the doctors or nurses when you don't understand what they're saying.

The questions are grouped by where you are in the process of cancer treatment. Not all of these questions will apply to you, but they should help get you started.

For more information on the type of cancer you have please contact your American Cancer Society toll free at 1-800-227-2345 or online at [www.cancer.org](http://www.cancer.org).

## When you're told you have cancer

1. Exactly what kind of cancer do I have?
2. How do I get a copy of my pathology report?
3. Where is the cancer located?
4. Has the cancer spread beyond where it started?

5. What's the cancer's stage? What does that mean?

6. How does this affect my treatment options and long-term outcome (prognosis)?

7. What are my chances of survival, based on my cancer as you see it?

8. How much experience do you have treating this type of cancer?

9. Will I need other tests before we can decide on treatment?

10. What are my treatment choices?

11. What treatment do you recommend and why?

12. What's the goal of my treatment?

13. Should I think about genetic testing?

14. Should I get a second opinion? How do I do that?

15. Should I think about taking part in a clinical trial?

## When deciding on a treatment plan

1. What are the chances the cancer will come back after this treatment?

2. What would we do if the treatment doesn't work or if the cancer comes back?

3. Will I be able to have children after treatment?

4. How much will I have to pay for treatment? Will my insurance cover any of it?

5. How long will treatment last? What will it involve?

6. Where will treatment be done?

7. What risks and side effects should I expect?

8. What can I do to reduce the side effects of the treatment?

9. How will treatment affect my daily activities?

10. Will I be able to work during treatment?

11. Will I lose my hair? If so, what can I do about it?

12. Will the treatment hurt? Will I have any scars?

## **Before treatment**

1. What should I do to get ready for treatment?

2. Will I need blood transfusions?

3. Should I change what I eat or make other lifestyle changes?

## During treatment

Once you have decided on treatment, you'll need to know what to expect and what to look for. All of these questions may not apply to you, but asking the ones that do may be helpful.

1. How will we know if the treatment is working?
2. Is there anything I can do to help manage side effects?
3. What symptoms or side effects should I tell you about right away?
4. How can I reach you on nights, holidays, or weekends?
5. Do I need to change what I eat during treatment?
6. Are there any limits on what I can do?
7. What kind of exercise should I do, and how often?
8. Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?
9. Will I need special tests, such as imaging scans or blood tests, and how often?

## After treatment

1. Do I need a special diet after treatment?
2. Are there any limits on what I can do?
3. What kind of exercise should I do now?
4. What type of follow-up will I need after treatment?
5. How often will I need to have follow-up exams and imaging tests?
6. What blood tests will I need?
7. How will I know if the cancer has come back? What should I watch for?
8. What are my options if the cancer comes back?

## Other questions I need answered

Along with the sample questions you've been given, be sure to ask any others you might have. For instance, you might need to know more about how long it will take to recover from surgery so you can plan your work schedule. Or, you may need to ask about insurance coverage or how you can get help paying for treatment. Write your own questions here.

## Month at a Glance

Month:

Year:

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.

# Month at a Glance

Month:

Year:

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.

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Month:

Year:

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.

# Laboratory Test Results Record

Your physician will keep records of your lab test values, but some people like to keep their own records.

Test	Function	Normal Levels	Low Levels	What You Can Do
Hemoglobin	Part of red blood cell that carries oxygen	12.0–18.0	Anemia	
Platelets	Helps clot the blood	150,000–400,000	Thrombocytopenia	See low blood counts
Absolute Neutrophil Count (ANC)	Type of white blood cell	1,500 or greater	Neutropenia	

	Date													
<b>Test</b>														
Hemoglobin														
Platelets														
ANC														

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.

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	Date													
<b>Test</b>														
Hemoglobin														
Platelets														
ANC														

For more information, contact OhioHealth CancerCall at (614) 566.4321 or 1 (800) 752.9119, Monday through Friday, 8 a.m. to 5 p.m.







## Chemotherapy Side Effects Worksheet

Medicines or drugs that destroy cancer cells are called cancer chemotherapy (chemo). Chemotherapy differs from surgery or radiation in that it treats the whole body. Usually chemotherapy is combined with other forms of therapy, like surgery, radiation, or biologic therapies.

Like all cancer therapies, chemotherapy drugs have side effects, some of which can be serious. It is important to keep track of any side effects you are having so your cancer care team can help you manage these. This worksheet will help you do that.

Listed on the following pages are the most common side effects experienced by patients receiving chemotherapy.

- You may have none, some, or all of these, or you may have side effects not listed here.
- With each side effect listed, there are suggestions on how to describe them to your doctor.
- Some side effects are more serious than others.

• **Ask your doctor which side effects he or she needs to know about right away.** Record these on the last page.

**Print a new worksheet for each week that you are receiving treatment and take the worksheet with you when you visit the doctor.**

### How to Use This Worksheet

- This worksheet covers 7 days of a chemotherapy cycle. You will need to print additional worksheets for each week of your cycle.
- Fill in the days of the cycle of therapy (for example, the day you start therapy is Day 1) and the dates for the week.
- For each day of the cycle, go down the column for that day and check the appropriate box describing the severity of each side effect. If you do not have a particular side effect, check the “None” box.
- Write down what medications you took to treat the side effect, if any.
- If you have a side effect that can be described as “severe”, notify your doctor right away.**

**Be sure to talk to your cancer care team about which side effects are most common with your chemo, how long they might last, how bad they might be, and when you should call the doctor’s office about them.**

## Chemotherapy Side Effects Worksheet

Date	/ /	/ /	/ /	/ /	/ /	/ /	/ /
Day of Chemotherapy Cycle	Day ____						
<b>Fever/Chills:</b> Write down your highest temperature for the day. None – Temperature 98.6° F Mild – Fever 98.6° F to 100.4° F Moderate – Fever 100.4° F to 104° F* Severe – Fever greater than 104° F*  Write any medicines taken for this here —>	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	Max Temp: _____°F <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Fatigue (Feeling Weak):</b> None Mild – Able to do normal activities with some effort Moderate – In bed less than half of the day Severe – In bed more than half the day*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Nausea:</b> None Mild – Can eat Moderate – Eating/drinking less than normal Severe – Can’t eat or drink*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Vomiting:</b> None Mild – Vomited once during the day Moderate – Vomited 2 to 5 times during the day* Severe – Vomited 6 or more times during the day*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Sore Mouth:</b> None Mild – Soreness or painless ulcer Moderate – Soreness or painful ulcer but can eat* Severe – Painful ulcer and cannot eat*  <b>*Let your doctor know about this right away.</b>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe

Date	/ /	/ /	/ /	/ /	/ /	/ /	/ /
Day of Chemotherapy Cycle	Day ____						
<b>Diarrhea:</b> Write down number of bowel movements per day. None Mild – Loose stools Moderate – Watery stools, many more than normal Severe – Constant or bloody, or causing you to feel dizzy*  Write any medicines taken for this here —>	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Constipation:</b> None Mild – No bowel movement for 2 days Moderate – No bowel movement for 3 to 4 days* Severe – No bowel movement for more than 4 days or swollen abdomen*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Loss of Appetite (Anorexia):</b> None Mild – Slightly decreased appetite Moderate – Usually not hungry Severe – Nothing looks good/unable to eat*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Pain or difficulty with swallowing:</b> None Mild – Pain but can eat Moderate – Pain requiring soft or liquid diet* Severe – Unable to eat at all*  <b>*Let your doctor know about this right away.</b>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe

Date	/ /	/ /	/ /	/ /	/ /	/ /	/ /
Day of Chemotherapy Cycle	Day ____						
<b>Swelling (Edema) in Hands or Feet:</b> None Mild – Swelling in hands or feet Moderate – Swelling extending up arm or leg* Severe – Swelling with pain or trouble breathing*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Allergic Reaction:</b> None Mild – Rash, No fever Moderate – Rash, fever <100.4F* Severe – Hives, fever > 100.4F* Difficulty breathing. Seek immediate treatment*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Itching or Rash:</b> None Mild – Scattered skin rash with redness/mild itching* Moderate – Generalized rash with sores* Severe – Rash with open sores*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Shortness of Breath:</b> None Mild – With exertion Moderate – With normal level of activity* Severe – At rest*  Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>*Let your doctor know about this right away.</b>							

Date	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
Day of Chemotherapy Cycle	Day ____								
<b>Muscle or Joint Pain:</b> None Mild – Sore but does not require medicine Moderate – Requires medicine for pain Severe – Pain medicine does not help* Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Numbness or Tingling in Hands or Feet:</b> None Mild – Tingling sensation Moderate – Tingling, some numbness Severe – Numbness interfering with function (for example, can't hold a coffee cup)* Write any medicines taken for this here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe

**LIST ANY OTHER SIDE EFFECTS YOU EXPERIENCE IN THE BOXES BELOW**

(Some other side effects include: hair loss, memory or concentration problems, easy bruising or bleeding, skin or nail changes like dry skin or color changes, urine or bladder problems)

**Side Effect:**

None  
 Mild  
 Moderate  
 Severe

Medications taken —>

**Side Effect:**

None  
 Mild  
 Moderate  
 Severe

Medications taken —>

**\*Let your doctor know about this right away.**

**Questions to Ask My Doctor**

Which side effects should I notify you about right away?

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**What Should I Do for the Side Effects That I Have?**

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**Notes**

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## External Radiation Side Effects Worksheet

External radiation therapy uses special equipment to deliver high doses of radiation to cancerous tumors, killing or damaging them so they cannot grow, multiply, or spread. Unlike chemotherapy, which exposes the entire body to cancer-fighting chemicals, radiation therapy affects only the tumor and the surrounding area.

On the following pages are the most common side effects experienced by patients receiving external radiation therapy.

- You may have none, some, or all of these, or you may have side effects not listed here.
- With each side effect listed below there are suggestions on how to describe them to your doctor.
- Some side effects are more serious than others.
- Ask your doctor which side effects he or she needs to know about immediately.** Record these on the last page.

### How to Use This Worksheet

- This worksheet will cover 6 weeks of radiation therapy. Fill in the date for the start of each week. For example, the week you start therapy is Week #1. If your therapy lasts beyond 6 weeks, you will need to print an additional worksheet.
- Side effects are listed in the left column.
- For each week, go down the column for that week and check the appropriate box describing the severity of each side effect. If you do not have a particular side effect, check the “None” box.
- Take this worksheet with you to your doctor visits.
- If you have a side effect that can be described as “severe”, notify your doctor right away.**
- At the end of the list, we have left spaces for you to add any side effects you may have that are not listed here. Use the same format to describe the severity of the symptom and any medications you took to treat it.

**\*Remember, your doctor may want to know immediately if you have some of these side effects.**

For more information on Radiation Therapy go to [www.cancer.org](http://www.cancer.org).

## External Radiation Side Effects Worksheet

Date	/ /	/ /	/ /	/ /	/ /	/ /
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
<b>General Symptoms</b>						
<b>Fatigue:</b> None Mild – Normal activity with effort Moderate – In bed less than half of day Severe – In bed more than of day*	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Skin Irritation</b> (in areas where radiation therapy is given): None Mild – Faint redness and scaling Moderate – Redness or moist peeling especially at skin folds* Severe – Swelling and moist peeling in large area or ulcer in skin*	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Fever/Chills:</b> Write down your highest temperature for the week. None – Temperature 98.6° F Mild – Fever 98.6° F to 100.4° F Moderate – Fever 100.4° F to 104° F* Severe – Fever greater than 104° F*	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Write any medications taken for this here —>						
<b>If You Are Receiving Radiation to the Head or Neck Area:</b>						
<b>Sore Mouth:</b> None Mild – Soreness, with no ulcers Moderate – Soreness or painful ulcer/able to eat* Severe – Painful ulcer and cannot eat or toothache*	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Write any medications taken here —>						
<b>Dry mouth (Xerostomia):</b> Decreased saliva Thick saliva No saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva	<input type="checkbox"/> Decreased <input type="checkbox"/> Thick <input type="checkbox"/> No Saliva
<b>*Let your doctor know about this right away</b>						



# External Radiation Side Effects Worksheet

Date	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
<b>If You Are Receiving Radiation to the Abdomen:</b>						
<b>Nausea:</b> None Mild – Able to eat Moderate – Eating/drinking less than normal Severe – Can't eat or drink* Write any medications taken here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Vomiting:</b> None Mild – Vomiting once Moderate – Vomiting 2 to 5 times in a day* Severe – Vomiting 6 or more times a day* Write any medications taken here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Diarrhea</b> (Write down highest number of bowel movements in a day): None Mild – 2 to 3 stools per day over normal Moderate – 4 to 6 stools per day over normal* Severe – Watery stools or 7 to 9 stool* Write any medications taken here —>	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	# of BMs: _____ <input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Change in Appetite:</b> Reduced food and fluid intake Call doctor if you are unable to eat or drink* Note any changes here —>	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink	<input type="checkbox"/> No change <input type="checkbox"/> Decreased <input type="checkbox"/> Unable to eat or drink
<b>*Let your doctor know about this right away</b>						



# External Radiation Side Effects Worksheet

Date	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
<b>If You Are Receiving Radiation to the Chest:</b>						
<b>Pain or difficulty with swallowing:</b> None Mild – Pain but can eat Moderate – Pain requiring soft or liquid diet* Severe – Unable to eat at all* Write any medications taken here —>	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<b>Soreness of the breast:</b> Write any medications taken here —>	<input type="checkbox"/> Yes <input type="checkbox"/> No					
<b>If You Are Receiving Radiation to the Pelvis (Females):</b>						
<b>Notify your doctor if you have any vaginal discharge or dryness*</b> Note any symptoms here —> Write any medications taken here —>						
<b>If You Are Receiving Radiation to the Brain:</b>						
<b>Notify your doctor if you have any of the following:</b> Headache* Seizure* Nausea/vomiting* Decreased hearing/loss* Note any symptoms here —>						
<b>*Let your doctor know about this right away</b>						



# External Radiation Side Effects Worksheet

Date	/ /	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
<b>LIST ANY OTHER SIDE EFFECTS YOU EXPERIENCE IN THE BOXES BELOW</b>							
Side Effect:		<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Side Effect:		<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
Side Effect:		<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe



# External Radiation Side Effects Worksheet

**Questions to Ask My Doctor**

Which side effects should I notify you about right away?

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**What Should I Do for the Side Effects That I Have?**

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**Notes**

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For More Information...  
 We're available to answer your questions about cancer. Contact us at 1-800-227-2345, or visit us online at [www.cancer.org](http://www.cancer.org).

*This guidebook was created by OhioHealth and derived from materials sourced by the American Cancer Society at Cancer.org and the National Comprehensive Cancer Network at NCCN.org.*



## About OhioHealth

*OhioHealth is a nationally recognized, not-for-profit, charitable, healthcare outreach of the United Methodist Church.*

*Based in Columbus, Ohio, OhioHealth has been recognized as one of the top five large health systems in America by Truven Health Analytics, an honor it has received six times. It is also recognized by Fortune as one of the "100 Best Companies to Work For" and has been for 13 years in a row, 2007–2019.*

*Serving its communities since 1891, OhioHealth is a family of 30,000 associates, physicians and volunteers, and a system of 12 hospitals and more than 200 ambulatory sites, hospice, home health, medical equipment and other health services spanning a 47-county area.*

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Español (Spanish)

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al (614) 566.3256.

繁體中文 (Chinese)

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。  
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