

Resource Guide

For finding information and support





Dear Patient and Family,

This booklet was designed to help you and your family. It includes information about cancer support, clinical trials and searching for health information online.

For more information about cancer, its treatment or other resources, call our Cancer Information Service line at 216-844-5432 or email cancerinfo@uhhospitals.org

To view our online patient education items, scan the QR code, or visit www.uhhospitals.org/seidmaneducation

We hope this information is useful and are honored that you have chosen UH for your care.

Sincerely,

Your Cancer Care Team and the UH Seidman Cancer Center
Office of Patient and Public Education



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This info is a general resource. It is not meant to replace your doctor’s advice. Ask your doctor or health care team any questions. Always follow their instructions.

Services we provide	Who can help	Ways they can help	For more info
Cancer Information	• Cancer Information Service line • Learning Resource Center	• Answer questions about cancer • Provide books and information about cancer • Perform searches on health topics	• Call or visit the Learning Resource Center 216-286-4636 • Located at main campus of UH Seidman Cancer Center –open to all patients • Call the Cancer Information Service line 1-800-641-2422
Symptom Management Supportive Care Palliative Care	• Supportive oncology/ Palliative care team	• Talk with you about your values, goals for care & treatment choices • Provide added support to help manage: – Pain – Fatigue (feeling tired) – Shortness of breath – Depression – Anxiety (worry) – Loss of appetite – Problems sleeping – Constipation – Nausea/Vomiting	• Speak with your doctor or nurse
Coping and Emotional Support	• Social workers • Supportive oncology team • Psychiatrists • Inpatient Palliative Care team (for patients in the hospital)	• Talk with you and your family about your concerns, worries or upset feelings • Provide the support you need • Address concerns about sexuality, self-image and/or changes in family roles	• Speak with your doctor or nurse
Help with Day-to-Day Needs	• Social workers	• Counseling and talking about your concerns • Referrals to local resources • Support for children dealing with the illness of a parent or grandparent	• Speak with your doctor or nurse

Ways We Can Help

Services we provide	Who can help	Ways they can help	For more info
Diet and Nutrition Support	Dietitians	- Answer your diet questions - Help you choose the best food and drinks during and after treatment	Speak with your doctor or nurse
Billing Questions	Financial counselors	- Answer your billing questions - Discuss our financial aid programs	Call 1-866-771-7266
Discharge Planning	- Care coordinators - Case managers - Social workers (inpatient)	- Make plans for extra care and items you may need at home once you leave the hospital - Work with your insurance company during your hospital stay	Speak with the doctor or nurse caring for you in the hospital
Cancer Rehab	- Occupational therapists - Physical therapists - Speech therapists - Physical medicine and rehabilitation doctors	- Use exercise and activity to help regain your strength and movement - Suggest ways to avoid falls and injuries - Manage the effects of lymphedema	- Speak with your doctor or nurse - Visit uhhospitals.org/cancerrehab
Art Therapy Music Therapy	- Art therapist - Music therapists	- Provide ways to reduce pain and stress, express your feelings and help you cope - Work with you and/or your family	Call 216-844-5432
Pet Pals	Pet Pals volunteers	Provide ways to reduce pain and stress, express your feelings and help you cope	Call 216-844-1504
Integrative Oncology	- Doctor - Acupuncturists - Massage Therapists	Provide ways to reduce pain and stress, express your feelings and help you cope	Speak with your doctor or nurse
Spiritual Care	- Spiritual care coordinator - Clergy	- Talk with you about your faith or spirituality - Offer prayer, listening and scripture reading	- Call 216-286-3871 or - Speak with your doctor or nurse
Help with Advance Directives	Social workers	Answer questions and help you complete a Living Will and/or Healthcare Power of Attorney	Speak with your doctor, nurse or social worker
Fertility resources	Oncofertility navigator	Provide resources about fertility options and resources	Call 216-844-5432 to learn more

Looking for Information?



Our patient education office can help get you free information about:

Cancer

- New diagnosis
- Metastatic cancer
- Genetic testing
- Clinical trials

Caregiver Support

- When Someone You Love is Being Treated for Cancer
- Caring for the Person with Cancer
- Talking with Children about Cancer
- When Your Parent has Cancer

Self-Care

- Eating Well
- Stress Management
- Quitting smoking
- Mindfulness

To Contact our Patient Education Office

Call the Cancer Information Service Line at **216-844-5432** or email cancerINFO@uhhospitals.org

Visit the Learning Resource Center on the first floor, past check-in Desk C, at University Hospitals Seidman Cancer Center at Cleveland Medical Center.

We can send items to patients seen at any of our cancer center sites.

Free Local Services



Northeast Ohio Cancer Wellness Centers

The cancer wellness centers below offer many free services for patients and their loved ones. Services include support groups, education programs and much more.

The Gathering Place

In Beachwood and Westlake

To learn more, call **216-595-9546** or visit **touchedbycancer.org**

Stewart's Caring Place

Serving the Akron area and nearby counties

To learn more, call **330-836-1772** or visit **stewartscaringplace.org**

Aunt Susie's Cancer Wellness Center

In Canton.

To learn more, call **330-400-1215** or visit **auntsusies.org**

Yellow Brick Place

In Youngstown; serves Mahoning, Trumbull and Columbiana counties

To learn more, call **234-228-9550** or visit **yellowbrickplace.org**

For Caregivers

Your family and loved ones may find these resources useful.



Books

Better Together: Navigating the Cancer Experience

by Jessica Walker, 2020.

Caregiver's Survival Guide: Caring For Yourself While Caring For A Loved One by Robert Yonover, 2018.

Co-Surviving Cancer: The Guide for Caregivers, Family Members and Friends of Adults Living with Cancer by Katie Brown, 2017.

Things I Wish I'd Known: Cancer Caregivers Speak Out - Third Edition

by Deborah J. Cornwall, 2016.

How to Help Children through a Parent's Serious Illness

by Kathleen McCue, 2011.

Local Cancer Wellness Centers

The Northeast Ohio cancer wellness centers on page 4 offer free caregiver support groups, education programs and other resources. Call or visit their websites to learn more.

For Caregivers

Your family and friends may find these resources useful.

Websites

Caring Bridge – caringbridge.org

A free online tool for sharing health updates with family and friends.

Family Caregiver Alliance – caregiver.org

Offers a wide range of information about caregiving.

Video and audio files are offered in many languages.

Cancer Support Community – cancersupportcommunity.org/caregivers

Offers videos and webinars on caregiving. There are also sections about talking with children, rights at work, and facing advanced cancer.

National Cancer Institute - cancer.gov.

In the search box, type Caregivers, then choose from the topics list. They also offer caregiver booklets that you can read online.

CancerCare – cancercare.org or call 1-800-813-4673

Offers several online caregiver support groups plus booklets, fact sheets and podcasts

These are suggested books and websites. They are not meant to take the place of medical advice or professional counseling. If you have any questions, please talk to your doctor, nurse, or social worker.



Searching for Online Health Info

Be Aware

Many people want to search online for answers after getting a cancer diagnosis. There is a lot of health info online, but what can you trust? Here are some tips.

Ask these questions when looking at a website:

- **Purpose: Is the website selling a product or giving free info?**
Does it support what your doctor says, or does it want to replace it?
- **Author:** Is the website sponsored by an honest, trusted group or person? Is the author upfront about who he or she is? Is it written by someone who has only personal experience but no medical background with the topic?
- **Current:** Is the website up-to-date?
- **Personal Info: Does the website respect your privacy?**
Or do you have to sign-in to get info?

Any website that makes promises like these below should **not** be trusted:

- “Treats all forms of cancer”
- “Makes cancers go away”
- “Shrinks malignant tumors”
- “Avoid surgery, radiation, chemo, or other normal treatments.”



Be careful if a website tells you to use its product instead of what your doctor suggests.

Trusted Websites for Cancer Information

These websites can help you find cancer info online. Always talk with your doctor, nurse, or social worker if you have any questions or concerns.

American Cancer Society
cancer.org

**National Center for Complementary
and Alternative Medicine**
nccam.nih.gov

National Cancer Institute (NCI)
cancer.gov

Cancer.Net
Sponsored by the American Society
of Clinical Oncology (ASCO).
cancer.net

Other Websites for Online Searches

- **National Institute on Aging - nia.nih.gov/health**
Offers information on many health topics
- **Medical Library Association - mla.org - click on For Patients**
Tips for finding health info online
- **MedlinePlus - medlineplus.gov**
A service from the National Library of Medicine

Talking to Others about Cancer

Good communication between with your family, friends and health care team can help improve your well-being and quality of life. Communicating about concerns and decision making is important during all phases of treatment and supportive care for cancer.



The goals of good communication in cancer care are to:

- Build a trusting relationship between you, your family, and your health care team.
- Help you, your family, and your health care team share information with each other.
- Help you and your family talk about feelings and concerns.

Talking about your feelings can help you deal with cancer.

- Choose a good listener.
- Choose a good time to share your feelings.
- Understand your feelings of anger or frustration.
- Be truthful to what your feeling are.

Cancer is hard to deal with all alone. Although talking about it may not be easy at first, most people find that sharing their thoughts and feelings is helpful.

You may need to find someone outside of your family to talk to. If you need help finding someone to talk to, please let us know.

Talking with your health care team

When you first learn you have cancer, daily life can feel like it is turned upside down. Learning more about your type of cancer and its treatment can help you feel more in control. It can also help you talk to your doctor about what treatment is right for you.

- **Ask as many questions as you need to.**
- **Don't worry if your questions seem silly or don't make sense.**
All your questions are important and deserve an answer.
- **Take someone with you when you see the doctor.**
Ask a family member or friend to join you so they can take notes, ask questions and listen to what your doctor says.
- **Take notes during your visit.** It's easy to forget everything that was said. You may also want to think about and write down important questions for your doctor before your visit.

Talking with your boss and coworkers

The response of coworkers about your cancer may differ. Some people may be a huge source of support, while others may be a source of anger or frustration. Some people mean well, but they don't know the right thing to say. Maybe they just don't know how to offer support. Others don't want to deal with your cancer at all. They may think that you aren't able to work as hard as before.

If coworkers seem unsupportive, it could be because they're anxious for you or for themselves. Your experience may threaten them because it reminds them that cancer can happen to anyone. Try to understand their fears and be patient as you try to regain a good relationship. But some people with cancer say that they get tired of trying to act cheerful around others. Many say that friendships change as they let go of their casual ones and give more time to the meaningful ones.

Relating to others at work

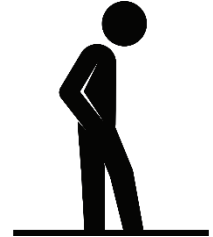
How do you relate to other people in your life when you go back to work? Does it feel good to return or do you worry how others will react? Here are some tips for returning to work:

- **Accept help.** When people offer to help, say yes, and have in mind some things that they could do to make your life easier. In this way, you will get the support you need, and they will feel helpful.
- **Talk to others.** If you find that a coworker's feelings about cancer are hurting you, try to resolve the problem with that person face-to-face. If it's still affecting your work after that, your manager, employee assistance counselor, or human resources office may be able to help.
- **Address problems that come up from the start.** Supervisors or coworkers may be able to help those around you understand how you want to be treated.
- **Try to keep up contacts during your recovery.** Coworkers will worry about you. But if they are kept up-to-date about your progress, they'll likely be less anxious and scared. Talk to them on the phone, send email, or ask a trusted friend or family member to do this for you.
- **Plan what you'll say about your cancer.** There is no right way to talk with others about your illness, but you do need to think about what you'll say when you're back on the job. Some people don't want to focus on their cancer or be linked in people's minds with the disease. Others are very open about it, speaking frankly with their boss or other workers to air concerns, correct wrong ideas, and decide how to work together. The best approach is the one that feels right to you.



Anxiety and Depression

It is normal to have many feelings after you learn you have cancer. These feelings can change from day to day, hour to hour and minute to minute. This section explains more about anxiety and depression and what to do if they happen. Talk with your doctor or nurse if you have any questions or concerns after reading this.



Anxiety

One feeling you may have is anxiety. Anxiety is a feeling of distress, worry, fear or panic. It is normal to feel anxious before, during and after treatment for an illness. Your body may react to the stress and worry about your health. You may notice that you:

- Don't feel like eating, or you eat more
- Have headaches or muscle pains
- Feel sick to your stomach or have diarrhea
- Feel shaky, weak, dizzy or your heart beats faster
- Have a tight feeling in your throat or chest or it's hard to breath
- Sleep too much or too little
- Find it hard to concentrate
- Have more pain
- Feel restless
- Find it hard to cope or keep your normal routine

Stress can keep your body from fighting disease as well as it should, so it's important to find ways to help manage anxiety.

Things you can do help manage anxiety

- **Talk with your doctor, nurse or social worker about how you feel.**
Tell us if you would like to speak with our spiritual care coordinator or someone who has special training in mental health.
- **Try deep breathing, progressive relaxation, meditation and/or exercise.** These things may help. A basic breathing technique is to sit or lie down in a comfortable position. Breathe in slowly through your nose. Hold your breath for a few seconds, and then do a long, slow exhale through your mouth. Do this breathing technique for 10 minutes, 2 to 3 times a day.
- **Do things that you enjoy and that take your mind off your illness.**
You might choose to listen to music, watch a favorite movie, spend time outdoors or talk to friends on the phone.
- **Find a quiet place to rest.**
- **Spend time in prayer or meditation.**
- **Listen to a guided imagery CD or recording.**

Your doctor might order a medicine to relieve your anxiety. Be sure to tell your doctor or nurse how this medicine works for you and if it causes any side effects.

Ways caregivers can help with anxiety

- Stay with the patient when they are anxious. Be calm and reassuring.
- Talk about and focus on other things you would have talked to your loved one about before they were diagnosed with cancer.
- Speak with a doctor, nurse or social worker if you need help giving support to the person you care about.

Depression

Many people with cancer feel sad or depressed. It is normal to feel sad, worried or depressed some days. But, if you have more than a day here and there where you feel sad and hopeless, this may be a sign of depression. When you're depressed, you may have very little energy, feel tired, get little joy from things that used to make you happy, or not want to eat.

Depression is sometimes a serious problem. If feelings of sadness and hopelessness seem to take over your life, you may have depression. Depression can be treated but you must speak up. If your health care team does not know you are depressed, they cannot help you feel better. When depression is not treated, people may have more problems. This is because they do not have the energy and concentration to follow through with all of the things their health care team asks them to do.

8 common signs of depression are listed below. Let your doctor or nurse know if you have one or more of these signs almost every day.

Early signs of depression

- A feeling that you are helpless or hopeless, or that life has no meaning
- Loss of interest in the hobbies, things you used to enjoy or being with family or friends
- Loss of appetite or no interest in eating
- Crying for long periods of time, or many times each day
- Sleep problems, either sleeping too much or too little
- Changes in your energy level
- Problems thinking, concentrating or making decisions
- Thoughts of killing yourself. This includes making plans or action to kill yourself, as well as frequent thoughts about death and dying.



If you ever feel like you will harm yourself or others, go to the nearest Emergency Room (ER), call 911 or contact the National Suicide Prevention Lifeline by calling or texting 988, or chatting online at www.988lifeline.org

Depression can be treated but you must speak up. Tell us if you feel really down or if feelings of sadness or despair seem to take over your life.

Call your doctor, nurse, social worker or mental health counselor right away if you:



- Have anxiety or panic that doesn't go away, gets worse or cannot be controlled
- Feel down, depressed or like you can't cope
- Feel that you are helpless or hopeless, or that life has no meaning
- Lose interest in hobbies, things you used to enjoy or being with family or friends
- Have a loss of appetite or no interest in eating
- Cry for long periods of time, or many times each day
- Have sleep problems, either sleeping too much or too little
- Have changes in your energy level
- Think often about death and dying
- Have depression that gets worse or comes back after getting better

Go to the nearest Emergency Room or call 911 right away if you:

- Have thoughts or plans of harming yourself or someone else
- Make plans or take actions to kill yourself
- Have chest pain, problems breathing or a rapid heart rate



**To reach the National Suicide Prevention Lifeline,
call or text 988 or chat online at www.988lifeline.org**

UH Connor Whole Health

The mission of the UH Connor Whole Health is to help people achieve optimal health. They offer therapies and services that work alongside traditional medical therapies to touch and heal the mind, body, and spirit. To learn more, call **216-285-4070** or visit **uhhospitals.org/connor**

Most services listed below are self-pay. The UH Connor Whole Health staff can provide more details about the cost of these services.

- Acupuncture
- Art and Music Therapy
- Chiropractic
- Guided Imagery
- Integrative Medicine Consultation
- Massage Therapy
- Mind-Body Wellness
- Yoga

Five Things You Should Know About Clinical Trials

1. Many cancer treatments used today are the result of past clinical trials.

Clinical trials are research studies that involve people. Clinical trials may also be called “studies.” They are the final step in a long process that starts with research in a lab. Many of the cancer treatments used today are the result of past clinical trials.

Clinical trials are designed to answer questions about new ways to:

- Treat cancer
- Find and diagnose cancer
- Prevent cancer
- Manage symptoms of cancer or side effects from its treatment

2. You have the chance to help others and improve cancer treatment.

This is one of the reasons why people choose to join a clinical trial. What we learn from the trial may help improve cancer treatment and help others. Other possible benefits to joining a clinical trial are:

- The chance to get a new drug or device that shows promise but is not yet proven
- Taking an active role in a decision that affects your life by looking at all your treatment choices

3. Strict guidelines are in place to protect your rights and safety.

The guidelines that clinical trials follow clearly state who will be able to join the study and the treatment plan. Protocols are written for each study. They are plans that explain what the trial will do, how the study will be carried out and why each part of the study is needed.

Federal rules help make sure that clinical trials are run in a fair and ethical way, so your rights and safety are protected.

4. We need everyone to think about joining a clinical trial.

We don't know enough about how certain drugs work in people of different races or gender. This is because in the past, most drug testing was done on white men. It's important that people of all backgrounds take part in clinical trials. That way, the results will be useful to all of us.

5. You have a choice.

You won't be enrolled in a clinical trial without your OK. If a clinical trial is an option, the research team will explain the trial to you before you decide if you want to join. They will share important details with you during a process called informed consent. They will explain the trial's purpose, tests and procedures, treatment and risks and benefits.

- Think about the possible benefits, risks and drawbacks during your decision-making process. You may want to talk about these things with your doctor or the people close to you.
- You will get the same level of expert health care whether you are, or are not, part of a clinical trial.
- You can stop being in a clinical trial at any time. If you decide to leave a study, your doctor will talk about other treatment options with you.

To learn more about clinical trials



➤ **Speak with your doctor or nurse.**

➤ **Call**

- Our Cancer Information Service Line at 1-800-641-2422
- The National Cancer Institute at 1-800-4CANCER. They can search their national clinical trials database for you. This is a free service.

➤ **Visit**

- clinicaltrials.uhseidman.org
- The National Cancer Institute website at **cancer.gov**

➤ **Read**

Taking Part in Cancer Treatment Research Studies by the National Cancer Institute.

For a free copy, call 216-844-5432.

Talking with Your Doctor about Clinical Trials

Talk with your doctor if you find a trial on our app/website that you'd like to know more about. Share with your doctor the trial's ID code, which is the series of letters and number before the trial's title.

Words to Know

Clinical research - medical studies that involve people to test new treatments and therapies. Also called clinical trials.

Inclusion Criteria - guidelines that make someone eligible for a clinical trial.

Exclusion Criteria - guidelines that make someone not eligible for a clinical trial.

Informed consent – a process in which patients are given important info, including risks and benefits, of a clinical trial, treatment or procedure. This is done to help people decide if they want to join the trial, be tested or treated.

Phase I (Phase 1) trials – the first step in testing a new treatment or device in humans. A phase I study tests the safety, side effects, best dose and timing of a new treatment. Phase I studies often include only a small number of patients.

Phase II (Phase 2) trials – a study that tests whether a new treatment works for a certain type of cancer or other disease. Phase II trials may also give more info about the safety of the new treatment and how it affects the body.

Phase III (Phase 3) trials—a study that tests the safety and how well a new treatment works compared with a standard treatment. Phase III trials may include hundreds of people.

Phase IV (Phase 4) trials—study a drug after it has been licensed and approved by the Food and Drug Administration (FDA). The FDA tracks its safety, and looks for more info about its risks, benefits and best use.

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