

**UNIVERSITY OF
MICHIGAN HEALTH**
MICHIGAN MEDICINE

Adolescent and Young Adult Oncology Program

Patient Guide

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Introduction

What is the purpose of this guide?

We want to share adolescent and young adult (AYA) cancer-specific information with you so that you and your family, friends, and caregivers can have up-to-date information on the resources available to you here at University of Michigan Health.

The guide is organized into different sections. Each section focuses on a specific area of life that is affected by cancer and its treatment. Each section also includes recommendations and information on resources and services that are available to help you. A separate section on sexual health and well-being is also available as a separate document.

What is AYA oncology?

AYA oncology is a growing field within the study of cancer (**oncology**). It looks at the needs of people between the ages of 15-39 who have a cancer diagnosis. A diagnosis is when you are identified as having a disease or illness, like cancer. A cancer diagnosis for teens and young adults affects and disrupts life in many significant ways.

If you are a cancer patient between the ages of 15-39, your treatment team understands that your needs are not the same as younger or older patients. Your lifestyle, activities, and priorities are unique and may include attending high school, going away to college, starting out in a career, or starting a family. People your age can share those experiences with each other, but most likely can't understand or talk about dealing with a cancer diagnosis and treatment.

What is the AYA Oncology Program at University of Michigan Health?

The AYA Oncology Program is a team of many different types of providers, including adult and pediatric oncologists, doctors who specialize in adolescents and adult and pediatric social workers, researchers, and others with expertise in supporting adolescents and young adults living with cancer. The AYA team will work with your treatment team to make sure you are receiving well-rounded, age-specific support and resources.

The AYA Oncology Program can connect you with:

- Fertility counseling and preservation options
- Emotional health resources
- Sexual health resources
- Nutrition counseling
- Art and music therapy
- School and job support
- Social workers
- Peer connection
- Community resources and AYA cancer organizations

Is the AYA Oncology Program available to patients being treated at both the pediatric and medical cancer centers?

Adolescents and young adults receiving treatment at either U-M Health C.S. Mott Children's Hospital or U-M Health Rogel Cancer Center may use the services of the AYA Oncology Program.

Are the AYA Oncology Program's services available to me no matter where my treatment occurs? Does it matter whether I'm getting inpatient or outpatient treatment?

The AYA oncology program services are available to you whether you're getting treatment in an inpatient or outpatient setting. The program focuses on supporting you at any point during your treatment or follow up.

Will I still be able to get AYA Oncology Program services when I transition off treatment?

The AYA oncology program works with you throughout your entire care journey – from the moment you learn about your cancer diagnosis, through the course of your treatment, and after your treatment has ended.

How do I contact the AYA Oncology Program?

The AYA Oncology program staff is available Monday through Friday, 8:30 am - 4:30 pm.

- E-mail the program: ayaprogram@med.umich.edu
- Ask a member of your oncology team to make a referral

To learn more about the program and its services, please visit: mottchildren.org/aya or scan the QR code.



Accessing Your Patient Portal at MyUofMHealth.org

This section gives you information about an important tool – the **MyUofMHealth Patient Portal**. The Patient Portal will help you connect with your treatment team (or a specific health care provider) and learn more about your care throughout the course of your treatment.

An introduction to the MyUofMHealth Patient Portal

What is the MyUofMHealth Patient Portal?

The MyUofMHealth Patient Portal gives you secure online access to parts of your **electronic medical record** (a record of all your health information stored on a computer). The Patient Portal allows you to securely use the internet to help manage and receive information about your health.

With MyUofMHealth, you can:

- Request medical appointments
- View your health summary from the MyUofMHealth electronic health record
- View your test results
- Request prescription renewals
- Access trusted health information resources
- Communicate with your treatment team
- Request an electronic copy of your medical records
- Pay your bills for the services you received from the health system

Will I be charged a fee to use MyUofMHealth?

No, there is no fee or cost to use the online Patient Portal. MyUofMHealth is a free service offered to all patients at University of Michigan Health.

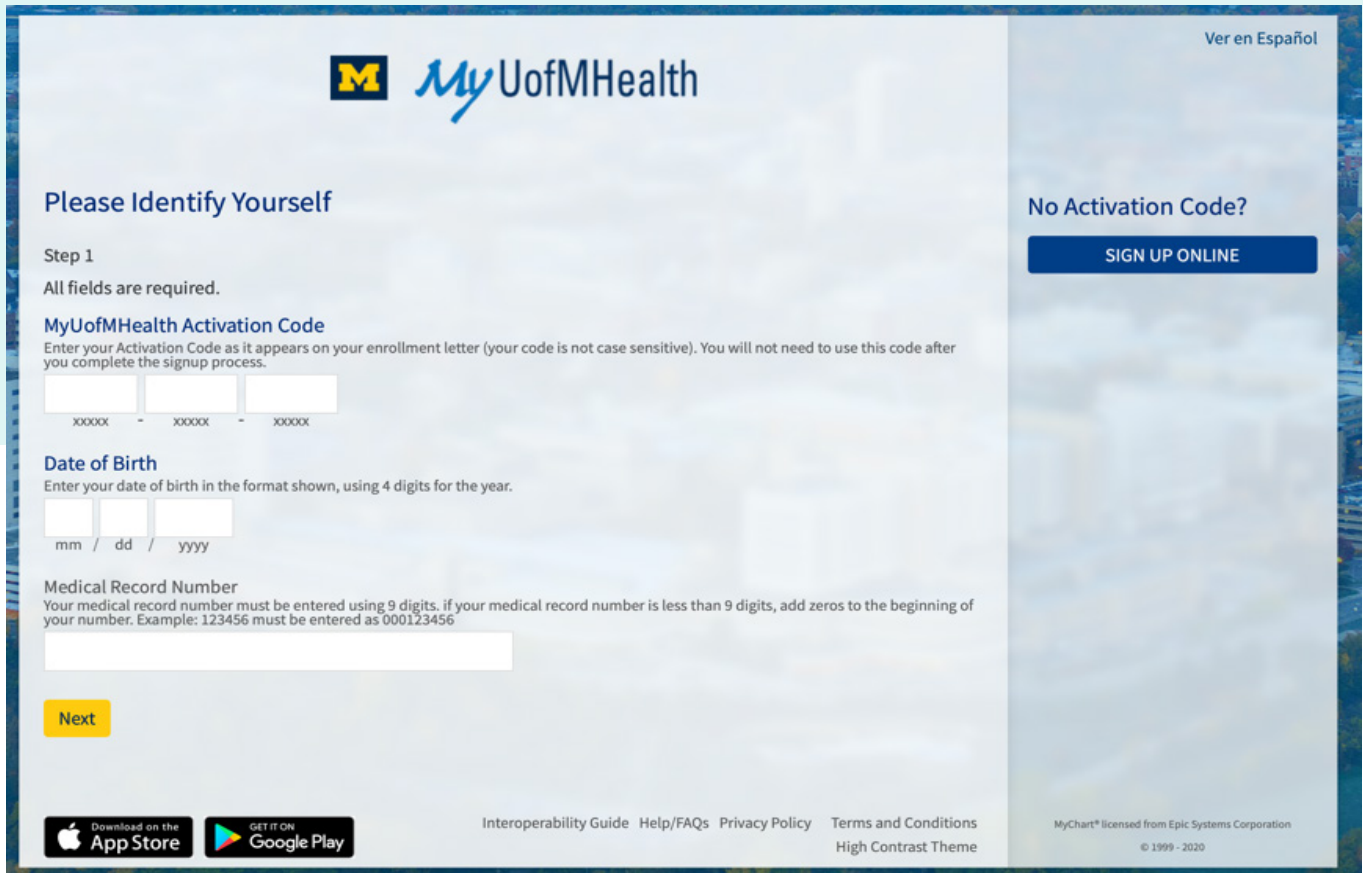
What do I need to have to use the MyUofMHealth Patient Portal?

You need access to a computer connected to the internet and an up-to-date browser (such as Microsoft Edge, Google Chrome, Safari, or Mozilla Firefox). You can also access MyUofMHealth from your smartphone. For Android or iPhone use, you can view your Patient Portal account by downloading the free MyUofMHealth app or the MyChart app (from Epic Systems Corporation).

MyUofMHealth Patient Portal account registration

How do I register for MyUofMHealth as an adult (age 18+)?

To access the MyUofMHealth Patient Portal and start the registration process, visit: MyUofMHealth.org/MyChart-PRD/Authentication/Login or scan the QR code. Choose the “New User Sign Up” on the home page and you will be taken to the sign-up page (see photo below).



The screenshot shows the MyUofMHealth Patient Portal registration page. The page title is "Please Identify Yourself" and it is labeled as "Step 1". It states that all fields are required. The registration process involves entering a MyUofMHealth Activation Code, a Date of Birth, and a Medical Record Number. The activation code field is a three-part input with placeholders "XXXXX - XXXXX - XXXXX". The date of birth field is a three-part input with placeholders "mm / dd / yyyy". The medical record number field is a single input with a placeholder "XXXXXXXXX". A "Next" button is located at the bottom left. On the right side, there is a "No Activation Code?" section with a "SIGN UP ONLINE" button. The page footer includes links for "Interoperability Guide", "Help/FAQs", "Privacy Policy", "Terms and Conditions", and "High Contrast Theme". It also mentions "MyChart® licensed from Epic Systems Corporation" and "© 1999 - 2020".

How do I get my MyUofMHealth activation code?

To use the MyUofMHealth Patient Portal, you will need an activation code. This code will let you login and create your own username and password. There are two ways to get an activation code:

- You can get an activation code at your clinic visit.
- You can request an activation code by completing an online request form.

How do I request a MyUofMHealth activation code if I don't have one?

To request a MyUofMHealth activation code, fill out the request form at: MyUofMHealth.org/MyChart-PRD/mobilepreloginsignup.html. You can also scan the QR code on the right to access the form.



For your security, any activation code you receive expires after 30 days if you don't activate your account. Once you activate your account, the activation code will no longer work. An activation code can't be reused.

If you need a new activation code, e-mail HIM-PatientPortal@med.umich.edu, or you can call Patient Portal Support at (734) 615-0872.

If your activation code is lost, expired, or not received, you still have options. You may contact Patient Portal Support at (734) 615-0872, Option 1, Monday through Friday from 7 am – 7 pm, or Saturday from 8 am – 1 pm. After your information has been checked, you'll get a new code.

How do I access my Medical Record Number (MRN)?

As a patient, you have a unique Medical Record Number (MRN) that is linked to your personal medical record. Your MRN must be entered using 9 digits (numbers). If your MRN is less than 9 digits, add zeros to the beginning of the number (for example, if your MRN was 123456, you would enter it as 000123456).

You can locate your MRN on these documents:

- A "Summary of Care" note (listed in the upper left corner) that you get after your appointment
- The label stickers on most medical information that your doctor gives you

Note: Your MRN is not the same as the account number that is on your billing statements. If you can't find your MRN, contact Patient Portal Support at (734) 615-0872 Monday through Friday from 7 am – 7 pm, or Saturday from 8 am – 1 pm.

After I click “Next” on the New User Sign Up page, it asks me to choose a username and password. What should I consider when deciding on a username and password?

Once you are signed up, you will need to choose a MyUofMHealth username and password. Choose a username and password that is easy for you to remember, but hard for others to guess. Your MyUofMHealth username must be between 5 and 20 characters (letters and/or numbers) but it can't include symbols (like @, #, \$, etc.). Once you pick a username, your MyUofMHealth username can't be changed.

Your MyUofMHealth password must be at least 8 characters and contain at least 1 number and 1 letter. Please keep in mind that only you will know your MyUofMHealth password. If you have lost or forgotten your username or password, please contact Patient Portal Support at HIM-PatientPortal@med.umich.edu or (734) 615-0872 on Monday through Friday from 7 am – 7 pm, or on Saturday from 8 am – 1 pm.

If I am an adolescent (age 13-17), can I register for a MyUofMHealth Patient Portal account?

Yes, if you are an adolescent (age 13-17), you may have full access to your own MyUofMHealth Patient Portal account. To request access, you will need to fill out and submit a different online form to get an activation code. Once you receive a code, then you can complete the sign-up process outlined above.

Where can I request an activation code as an adolescent?

Please use the following link to access the MyUofMHealth Adolescent Access Request Form: MyUofMHealth.org/MyChart-PRD/mobilepreloginsignup.html.

You can also scan the QR code to access the form.



Who do I contact if I still have questions about account registration?

You may email HIM-PatientPortal@med.umich.edu, or you can call Patient Portal Support at (734) 615-0872, Option 1, Monday through Friday from 7 am – 7 pm, or Saturday from 8 am – 1 pm.

MyUofMHealth proxy access

What is proxy access?

Proxy access means using the Patient Portal to view another patient's health information with permission. Proxy access is often used by a parent or legal guardian to see their child or adolescent's account. Proxy access can change depending on your age and other factors. Generally, proxy access follows the guidelines below (with a few exceptions):

- **Patients ages 0-12:** Parents or legal guardians have **full access** to a child's account.
- **Patients ages 13-17:** Parents or legal guardians have **limited access** to a child's account.
 - Parent and legal guardian access includes seeing information on allergies, immunizations, demographics, messages with providers some upcoming and past appointments (including video visits), after-visit summaries, test results, and medications. Information entered into the patient's chart by most providers is also included.
- **Patients ages 18 or older:** Since the patient is now a legal adult, parents or legal guardians no longer have access to the patient/s account. If they want to continue to have access, they will need to complete an Adult to Adult Proxy request.

If you are an adult (age 18 or older) and you want to share access to your Patient Portal with someone, you can approve an Adult to Adult Proxy request for them. You can request this using an online form at any time. Please use the following link to access the MyUofMHealth Adult to Adult Proxy Request Form: MyUofMHealth.org/MyChart-PRD/mobilepreloginsignup.html.



Who do I contact if I still have questions about proxy access?

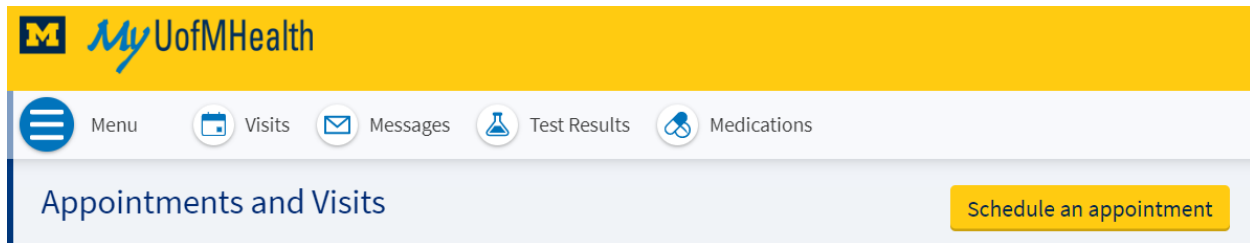
You may e-mail HIM-PatientPortal@med.umich.edu, or call Patient Portal Support at (734) 615-0872, Option 1, Monday through Friday from 7 am – 7 pm, or Saturday from 8 am – 1 pm.

Scheduling and canceling appointments in MyUofMHealth

Can I schedule an appointment through the MyUofMHealth Patient Portal?

If so, how?

You can schedule or request an appointment at any clinic you have completed an appointment at within the last 3 years by selecting the “Schedule an appointment” button under the Visits menu.



How do I cancel an appointment through the Patient Portal?

Most appointments can be canceled in MyUofMHealth. Open the visit you’d like to cancel by going to the Visits menu and finding your appointment under “Upcoming Visits.” If the appointment is in less than 24 hours, you will not be able to cancel the appointment through MyUofMHealth. To cancel an appointment within 24 hours of the appointment, call the front desk of the clinic where you will be seen to speak with a staff member.

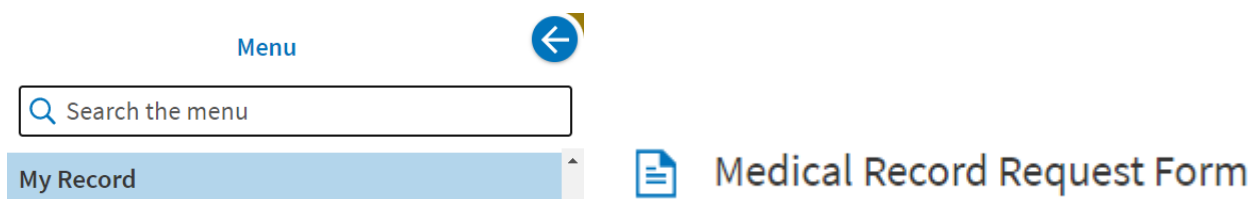
MyUofMHealth and my electronic medical record

How does the MyUofMHealth Patient Portal access my electronic medical record?

The MyUofMHealth Patient Portal gives you personalized and secure online access to parts of your medical record. The sections below will answer some of the common questions about this form of electronic medical record access, as well as how you can find certain resources if this access doesn’t meet your needs.

How can I get electronic access to my medical record through MyUofMHealth?

If you have a MyUofMHealth account, you can submit requests for copies of medical records from the Patient Portal by using the Medical Record Request Form listed under the “My Record” section of the menu. If you have an urgent need to get copies of your medical records, please call the Release of Information Unit at (734) 936-5490, Monday through Friday, 8 am – 5 pm.



If some of my health information on MyUofMHealth is not correct.

What should I do?

You may e-mail HIM-PatientPortal@med.umich.edu, or you can call the Health Information Exchange Unit (HIE) at (734) 615-0872, Option 2, Monday through Friday, 7:30 am – 4 pm. They will work with you and your health care provider to make sure your medical record is correct.

To learn more about your protected health information, please visit: UofMHealth.org/patient-visitor-guide/protecting-your-privacy-hipaa or scan the QR code.



Can I access notes from my health care provider or treatment team from recent appointments?

Yes, University of Michigan Health patients have access to clinical notes in the MyUofMHealth Patient Portal. Once you are logged in to your Patient Portal account, click on the Visits icon from the menu at the top of your screen. Scroll down to “Past Visits” and click “View notes” (available for most past visits).

Why might some of my notes not be available after my appointment?

- Most notes are available to view immediately after they are completed.
- Notes are not available until the provider has finished their documentation (writing their notes).
- Research notes are not shared until after the study is completed.
- All notes are available by request through Release of Information.

What should I do if I don't understand my health information?

- You can talk about any questions with your health care provider at your next office visit.
- You can also read about many different health topics in your Patient Portal for more information.
- You can send your provider a message through the Patient Portal.

If I send a message to a provider, when can I expect a reply?

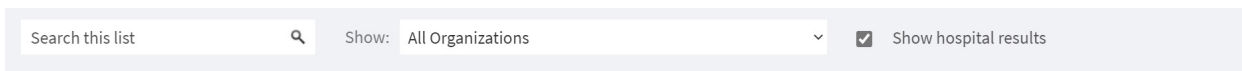
You will usually get an answer within 3 business days (Monday through Friday). Please note that MyUofMHealth should not be used for urgent situations. Please call the nurse line at (734) 936-9814, go to your nearest medical center if you need immediate attention, or call 911 if it is an emergency.

When can I see my test results in MyUofMHealth?

You'll be able to see most test results immediately after they are finalized. Because most results are released immediately, you may see the results before your health care provider has had a chance to review them.

Why can't I see some of my test results in MyUofMHealth?

If a non-U-M provider ordered your tests, they will not appear in MyUofMHealth even if you got your test at U-M. If your tests were done in the Emergency Room or as part of a hospital admission, click on the "show hospital results" button on the "Test Results" screen. This is only accessible through a web browser.



What if I still have questions?

If you still have questions about MyUofMHealth that were not answered in this section, please visit the MyUofMHealth Patient Portal Frequently Asked Questions (scroll down to see the FAQ): [MyUofMHealth.org/MyChart-PRD/Authentication/Login?mode=stdfile&option=faq](https://myuofmhealth.org/MyChart-PRD/Authentication/Login?mode=stdfile&option=faq). You can also scan the QR code.

There is also another FAQ from University of Michigan Health's Health Information Management team, available at med.umich.edu/1libr/HIM/PatientPortal.pdf. You can also scan the QR code.

If you still need more help, please contact Patient Portal Support at HIM-PatientPortal@med.umich.edu or (734) 615-0872, Option 1, Monday through Friday from 7 am – 7 pm, or Saturday from 8 am – 1 pm.



Cancer and Cancer Treatment

Cancer and understanding a cancer diagnosis: A brief introduction

What is cancer?

Our body is made up of all different kinds of cells. Cells are always growing and dividing, some faster than others (depending on the type). Cancer happens when something goes wrong in the cells and they start growing and dividing too fast. These new cells don't work and they keep growing, dividing and spreading, leading to cancer.

The type of cell that this happens to is what determines the type of cancer. Here are a few examples:

- Cancer in the white blood cells is called leukemia
- Cancer in the lymph nodes is called lymphoma
- Cancer in the soft tissue cells is called sarcoma

Cancer spreads to different parts of the body by traveling through the bloodstream or **lymphatic fluid** (clear fluid that carries cells throughout your body to help you fight infections). If cancer is present in many other spots than the **primary site** (where the cancer started), this is known as **metastatic disease**. Common sites of **metastases** (places where the cancer has moved to and grown) include the lung, the liver, and bones.

What do providers consider when making a cancer diagnosis?

There are several tools doctors use to make a cancer diagnosis. They will typically use some combination of the following:

- **Laboratory test (or labs):** Your doctor will check some combination of lab tests (testing a sample of your blood, urine, or another substance). Most commonly, they'll check:
 - **Complete blood counts (CBC):** looking at the types of blood cells you have and how many there are
 - **Tumor markers:** things tumor cells are releasing that can be measured
 - **Electrolytes:** minerals in your blood
 - **Inflammatory markers:** signs of inflammation in the body caused by disease and infection

- **Lumbar puncture/spinal tap:** Some cancers can hide in spinal fluid, so your oncologist may check with a procedure called a spinal tap.
- **Imaging/scans:** Your doctor can order **scans** (tests to take pictures of what’s going on inside your body) to get a better look at your cancer and see whether it has spread.
 - A **CT scan** or **MRI** helps look at the shape and location of the cancer.
 - **PET scans** look at the activity of cancer cells, which is a way to see where your cancer is located and track its response to treatment.
- **Bone marrow biopsy:** This involves taking a sample of your bone marrow through a needle in your hip bone. They will look at the sample to see if there is cancer there and what type of cancer it is.
- **Biopsy:** This procedure involves surgically removing a piece of tumor so a pathologist can look at it under a microscope.

Cancer treatment

What does cancer treatment mean, and what types of treatment are available?

Different cancer types are treated differently. The goal is to remove all the cancer cells from your body. To do this, you may need a combination of different treatment types. The main types of cancer treatment are **chemotherapy, immunotherapy, radiation, and surgery**. You may receive one or more of these treatments.

- **Chemotherapy:** Chemotherapy, or “chemo,” is a treatment that uses medication to stop the growth of cancer cells. There are many different types of chemo. Most cancers require treatment with chemotherapy.
- **Immunotherapy:** Immunotherapy is a treatment that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases.
- **Radiation:** Radiation helps shrink tumors. You may get this right after your diagnosis to shrink your tumor and make surgery easier, or you may get this later after receiving chemotherapy and/or surgery to help get rid of any remaining cancer cells. Not all cancers require radiation. If you do require radiation, you will meet with a **radiation oncologist**, a doctor who is specially trained to give radiation.
- **Surgery:** Some cancers can be surgically removed. Sometimes surgery is the only treatment necessary. Sometimes you may need a combination of surgery and other treatments. Some people are not eligible for surgery. Your doctor will talk about this with you.

What are the common side effects of cancer treatment?

Short-term effects

While different chemotherapy drugs can cause different side effects, most have the following in common:

- **Hair loss:** Complete hair loss can be expected with almost all chemo treatments. Some patients complain hair loss can cause some itchiness, so some patients decide to shave their hair off when this starts. When and how fast hair loss happens is different for every patient. The important thing to remember is this is temporary, and that hair grows back when chemo is done.
- **Nausea and vomiting:** Most (but not all) chemo drugs cause some nausea and vomiting. However, there are many anti-nausea medications, talk with your doctor to learn more about these options.
- **Low blood counts:** Chemotherapy works by targeting cells that are growing and dividing very quickly. Chemotherapy can't tell the difference between cancer cells and normal cells in the body that divide quickly, which include your blood cells. This can cause low blood cell counts for different types of blood cells.
 - **Red blood cells:** Red blood cells have **hemoglobin**, a protein which carries oxygen. This is how oxygen gets delivered throughout your body. When you have low red blood cells and your hemoglobin is low, this is called **anemia**. Symptoms of anemia include tiredness, looking pale, shortness of breath, feeling like your heart is racing, and headaches.
 - **Platelets:** Platelets in your blood are what help stop bleeding when you are injured. When your platelets are low, you may notice that you bruise easily, you get red dots over your body (called **petechiae**, pronounced "puh-TEE-kee-ee"), you have frequent nosebleeds, or you bleed easily when you brush your teeth.
 - **White blood cells:** White blood cells help fight infection. When your white blood cells are low, you are more likely to get infections and you may not be able to fight them off. Your treatment team will talk about your **neutrophil** count a lot. Neutrophils are a type of white blood cell that help fight bacterial infections.

Long-term effects

Not everyone undergoing cancer treatment will experience long-term effects, but some people are at risk for the following:

- **Cardiotoxicity:** Some forms of chemotherapy can affect your heart and make it work harder. If you are receiving one of these forms of chemo, your doctor will periodically check your heart function with an **echocardiogram**, even after you are done with chemotherapy. An echocardiogram uses sound waves to create pictures of your heart that show how blood is flowing through your heart. Your risk of cardiotoxicity depends on how big a dose of the chemotherapy you received.
- **Decreased fertility:** Reproductive cells divide quickly, like cancer cells, so they can be affected by chemotherapy. Your doctor should talk to you about some form of **fertility preservation** (procedures that protect your ability to have children if you want to) before starting treatment. Don't be afraid to ask.. This is also something your oncologist will watch and check in with you about over the years.
- **Secondary cancer:** Some chemotherapy does come with a small risk of causing a treatment-related cancer, sometimes a few years after treatment has finished. While the chance is small, your doctor will continue to watch for any signs of a new cancer after your treatment has ended.



Who is typically on my treatment team?

Below is a list of the health care providers that are typically part of most treatment teams:




- **Oncologist/attending physician:** This is a doctor who has gone through all the required training to become an **oncologist** (a doctor who specializes in the treatment of cancer). You will have a **primary attending**, who will be your main oncologist, overseeing your care.
- **Oncology fellow:** This is a doctor who has completed their general training and is now doing special training to become an oncologist. You may have a **primary fellow** assigned to you who will be directly responsible for your care.
- **Oncology nurse practitioner/Oncology advanced practice provider:** This is a nurse or a physician assistant who has had extra training to be able to treat patients with cancer. You may have a **primary nurse practitioner** or an **advanced practice provider** assigned to you who will be directly involved in your care.
- **Nurses:** You will also have nurses, including both **inpatient** nurses (if you are admitted to the hospital) and **outpatient** nurses (if you receive treatment in the infusion center) who know you well and who are great resources.

More resources on cancer and cancer treatment

Where can I find more information about cancer and cancer treatment?

<p>National Comprehensive Cancer Network (NCCN)</p> <ul style="list-style-type: none">• “Adolescent and young adult (AYA) cancer” section on pages 4-7 of the Adolescent and Young Adult Cancer NCCN Guidelines for Patients®• Link: nccn.org/patients/guidelines/content/PDF/aya-patient.pdf	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: Cancer Basics”• Link: cancer.net/navigating-cancer-care/cancer-basics	



I am interested in learning more about how a cancer diagnosis is made. Where can I learn more about the cancer diagnosis process?

<p>National Comprehensive Cancer Network (NCCN)</p> <ul style="list-style-type: none">• “Testing and treatment” section on pages 17-26 of the Adolescent and Young Adult Cancer NCCN Guidelines for Patients®• Link: nccn.org/patients/guidelines/content/PDF/aya-patient.pdf	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: Diagnosing Cancer”• Link: cancer.net/navigating-cancer-care/diagnosing-cancer	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: Questions to Ask Your Health Care Team”• Link: cancer.net/navigating-cancer-care/diagnosing-cancer/questions-ask-your-health-care-team	




I am interested in learning more about some of the common side effects associated with cancer. Where can I learn more about common side effects?

<p>National Comprehensive Cancer Network (NCCN)</p> <ul style="list-style-type: none">• “Testing and treatment” section on pages 17-26 and “Care planning” section on pages 39-43 of the Adolescent and Young Adult Cancer NCCN Guidelines for Patients®• Link: nccn.org/patients/guidelines/content/PDF/aya-patient.pdf	
<p>National Cancer Institute (NCI)</p> <ul style="list-style-type: none">• “Side Effects of Cancer Treatment”• Link: cancer.gov/about-cancer/treatment/side-effects	
<p>American Cancer Society (ACS)</p> <ul style="list-style-type: none">• “Managing Cancer-related Side Effects”• Link: https://www.cancer.org/cancer/managing-cancer/side-effects.html	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: How Cancer is Treated”• Link: cancer.net/navigating-cancer-care/how-cancer-treated	

I am interested in learning more about what cancer treatment means, what treatments are available and what certain treatments involve. Where can I learn more about these topics?

<p>National Comprehensive Cancer Network (NCCN)</p> <ul style="list-style-type: none">• “Testing and treatment” section on pages 17-26 of the Adolescent and Young Adult Cancer NCCN Guidelines for Patients®• Link: nccn.org/patients/guidelines/content/PDF/aya-patient.pdf	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: How Cancer is Treated”• Link: cancer.net/navigating-cancer-care/how-cancer-treated	

I am interested in learning more about some of the other providers who might be involved in your treatment team or who contribute to the cancer care and cancer treatment. Where can I learn more about these individuals?

<p>National Comprehensive Cancer Network (NCCN)</p> <ul style="list-style-type: none">• “Testing and treatment >> Care team” section on page 21 of the Adolescent and Young Adult Cancer NCCN Guidelines for Patients®• Link: nccn.org/patients/guidelines/content/PDF/aya-patient.pdf	
<p>CancerCare</p> <ul style="list-style-type: none">• “Your Health Care Team: Understanding Their Roles”• Link: cancercare.org/publications/59-your_health_care_team_understanding_their_roles	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Navigating Cancer Care: The Oncology Team”• Link: cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/oncology-team	

I am interested in resources that are available to support me as I navigate my cancer diagnosis and its treatment. What is available?

American Society of Clinical Oncology (ASCO)

- “Navigating Cancer Care: For Young Adults and Teenagers”
- Link: cancer.net/navigating-cancer-care/young-adults-and-teenagers



American Society of Clinical Oncology (ASCO)

- “Navigating Cancer Care: Managing Your Care”
- Link: cancer.net/navigating-cancer-care/managing-your-care



I am interested in learning more about cancer-related terms that I might hear throughout the course of my treatment. Where can I learn more about cancer-related terms?

National Cancer Institute (NCI):

- NCI Dictionary of Cancer Terms
- Link: cancer.gov/publications/dictionaries/cancer-terms



American Society of Clinical Oncology (ASCO)

- “Navigating Cancer Care: Cancer Terms”
- Link: cancer.net/navigating-cancer-care/cancer-basics/cancer-terms



Clinical Trials

This section gives you information on clinical trials for cancer patients. It talks about what a clinical trial is, how to find clinical trial options, and the clinical trial enrollment process. Learning about clinical trials can help you decide whether a clinical trial might be right for you.

What is a clinical trial?

Clinical trials are studies of new medications, procedures, and other treatments in people. Researchers and doctors use clinical trials to develop new treatments for different cancers. Through clinical trials, researchers find new ways to improve treatments and the quality of life for people with certain cancers. Clinical trials study how safe and helpful certain tests and treatments are for patients.

What are the different phases of clinical trials, and what do they mean?

Clinical trials are divided into different phases, or steps. These phases build on one another, with each one answering specific research questions over time. It is important for you to know about clinical trial phases, because it will give you an idea of how much is known about the treatment that is being studied.

- **Phase 0 (also called a pilot or feasibility study):** A Phase 0 clinical trial is used to check on the time, cost, and success rate of a study with a small group. This helps researchers decide if or how it should be expanded to a larger group.
- **Phase I:** A Phase I clinical trial is used to find the right dosage of a test drug or the best way to give a drug (for example, if it works better to give the drug by mouth or in a vein).
- **Phase II:** A Phase II clinical trial is used to find out if the new treatment works against the cancer, or whether the new treatment has good or bad effects on the patient.
- **Phase III:** A Phase III clinical trial compares the new treatment to a current one to see if it works better or worse.
- **Phase IV:** A Phase IV clinical trial looks at the long-term safety and effectiveness of the new treatment.

Why is it important to have information about clinical trials?

When you are making decisions about your care, it is important for you to know all your treatment options to make an informed decision about your treatment. Clinical trials are one of those options.

Do I qualify for clinical trials?

Please talk to your treatment team to find out whether there is a clinical trial appropriate for you.

They can help guide you and tell you if you would qualify for a clinical trial.

Is there a cost to be in a clinical trial?

There can be costs to be in a clinical trial. The costs fall into two areas: patient care costs and research costs.

- **Patient care costs:** These are costs related to treating your cancer. Patient care costs are typically covered in part by insurance. They include things like:
 - Doctor visits
 - Hospital stays
 - Standard treatments
 - Treatments to improve symptoms or side effects
 - Blood tests
 - Imaging tests like x-rays
- **Research costs:** These are costs related to the clinical trial. These costs may not be covered by health insurance. Sometimes these costs can be covered by the clinical trial’s sponsors. Some of these costs can include:
 - The study test or drug
 - Blood tests that are only done for research (not treatment)
 - More imaging tests

It is important for you to talk with your treatment team about what costs you may have if you join a specific clinical trial.

How do I find the right clinical trial for me?

You should talk with your treatment team about whether a clinical trial might be right for you. There are trials available at both C.S. Mott Children’s Hospital and Rogel Cancer Center. You can find clinical trial opportunities online at:

Rogel Cancer Center

- “Find a Clinical Trial” online search
- Link: RogelCancerCenter.org/clinical-trials/find-clinical-trials



C.S. Mott Children’s Hospital

- “Cancer Clinical Trials (Pediatric)”
- Link: MottChildren.org/conditions-treatments/ped-cancer/clinical-trials



Physical Health & Well-being

How will my cancer diagnosis affect my participation in activities?

Every patient will experience different side effects during and after their treatment, based on their personal treatment plan. Your activity level will likely be affected in some way, but how much it will be affected is different for each patient. Your ability to participate in physical activities might change because of feeling tired or weaker, having nausea or vomiting, or having low blood counts that put you at high risk for bleeding and infection.

However, being physically active before, during, and after cancer treatment has proven benefits, and treatment teams encourage all patients to stay active in some way throughout their cancer journey.

What are side effects of treatment that could limit my physical activity?

Common side effects from treatment that may make it hard to be active include feeling tired or nauseated and changes to your body from surgery or radiation. Your providers can talk with you about each step of your treatment. They can also explain how your participation in activities may be affected by what you will experience.

- Chemotherapy can reduce the number of cells you have to help your blood clot, carry oxygen, and fight infections. When your cell counts are low, you may not feel very energetic to do physical activities. This is usually only temporary, and when your blood counts improve, you can expect to feel better. Some chemotherapy medications can also cause changes in balance that might affect how you feel you are able to move your body.
- Radiation can lead to skin changes that might make your skin feel more sensitive or less flexible in certain areas. There are treatments to help improve this.
- Surgery may also cause you to be less active while you recover.

Even though your treatments may reduce your activity level, there are always options to stay active in some way. Your care team can help you deal with this and find safe activities that work for you.

What physical activity is safe during treatment?

Talk to your treatment team before you start a new physical activity that you had never done before your cancer diagnosis. During treatment, daily activities such as walking and doing tasks around the house are generally safe and recommended.

- Non-contact sports (such as swimming, yoga, stretching, biking, dancing, and jogging) can be safe if you have the energy and you are not concerned about your balance.

- If you swim, make sure you know the right care for any central line access. Swimming in large lakes and pools is generally safe. Avoid swimming in smaller bodies of water that might have a higher risk of infection from bacteria.

Exercise can improve physical functioning, tiredness, pain, self-esteem, social interactions, and anxiety while going through treatment. There is evidence that exercise can improve general life satisfaction for cancer survivors and can even help lower the risk of getting another cancer later in life. Exercise has been shown to improve cardiovascular (heart) fitness, muscle strength, and body composition (how much fat, muscle, bone, and water your body is made of). Although patients receiving chemotherapy and radiation therapy may need to participate in activities at a lower intensity level or for shorter periods of time, you're encouraged to stay as active as possible during treatments.

How much exercise can I do?

How much you exercise and how hard you exercise will depend on how you feel and what treatments you're getting. Remember, it's always a good idea to talk to your oncology team about safe physical activities.

- When your blood counts are low, you may feel more tired and you may want to stay away from crowded places like gyms because of the risk of getting an infection.
- On days when you don't feel like exercising, it is encouraged you do 10 minutes of light activity (such as walking or moving your arms).
- If you have multiple issues that affect your ability to exercise, please talk to your team about what exercises would be safe and possible.
- If you feel off-balance or have some numbness or tingling in your extremities (your hands, feet, etc.) from your treatment, it is recommended you talk with your provider before starting any activity. In this case, they may recommend changes to your activity (such as using a stationary reclining bicycle instead of walking on a treadmill).

If you were not very active before your diagnosis, remember to start slow with low-intensity activities (such as stretching and slow walks) until you feel like you can start to do more. The American College of Sports Medicine recommends working up to exercising 30 minutes a day for at least 3 days a week. This recommendation is considered safe and effective to help improve anxiety, depression, tiredness, and quality of life. They give the following definitions for different intensity levels of activity:

- **Moderate activity:** Exercising at a pace where you can talk but can't sing. Examples: fast walking, light biking, exercises in water, dancing.
- **Vigorous activity:** Exercising at a pace where you have trouble talking and you may be out of breath. Examples: jogging, tennis, fast biking.

They also recommend strength training 2 days a week. You don't have to go to a gym for strength training. You can use your own body weight or items around your house to help you. Start by doing 10-15 repetitions of a strength exercise using light effort, and slowly build up to medium or hard effort for 8-12 repetitions. You can repeat that 2-4 times during your workout session. Make sure to have a rest day in between each strength training session.

What physical activities should I avoid during treatment?

Because every person has a different treatment course and timeline, activities that you should avoid might be different based on your diagnosis.

- You should not do contact sports or activities with a risk of falling (mountain biking, riding ATVs, jumping on a trampoline) because of the risk of bleeding when you have a low blood count. Feet on the ground activities may be okay after talking with your provider.
- Strength training is generally safe. However, if you are receiving chemotherapy that affects your heart, you should talk with your provider before you do any activities where you'll be holding or handling a lot of weight.

Will I be able to be active at the level I was before my diagnosis?

The hope is that after your treatment is over, you will be able to participate in the activities you would like to do. The long-term effects of treatment are different for each person. The most important way to make sure you will be able to be as active as you would like is to continue listening to your body, moving when you are able and resting when you need to.

What services are there to help me continue to be physically active, and how can I access these?

Cancer treatment is a team effort! There are a lot of groups who can help you stay active during your treatment time. **Physical therapy and occupational therapy** (types of therapy that help you regain strength, movement, and skills for everyday activities) are the most common resources, and you can access them at the hospital or at a clinic near your own home. Also, these teams can see you if you are ever in the hospital so you can be sure to get the therapies you need. They offer many ways (both in your hospital room and out) to stay active during your hospital stay. You may also be referred to the Physical Medicine and Rehabilitation team or the Orthotics and Prosthetics team. These teams can help provide higher level rehabilitation needs as well as adaptive devices to help you if your treatment has affected your walking, your strength, or the shape of the body parts you use to move.

Who can I contact if I have questions about physical activity during or after treatment?

If you have questions about exercise during your therapy, you can always send a message to your care team through your Patient Portal. You can also call the nurse line at (734) 936-9814 or call the Cancer Answerline at (800) 865-1125. Get an emergent evaluation at a hospital and call the after-hours number provided to you if you experience any of the following symptoms:

- Shortness of breath
- Dizziness or passing out
- Severe pain
- Not being able to feel or move your body as you used to

What are the common side effects of treatment and what do they look like?

Peripheral neuropathy

Peripheral neuropathy is any change in feeling, strength, or pain that can happen in your nerves while you're taking or after you take certain medications, or because of surgeries.

Symptoms include:

- Burning, tingling, or prickling feeling (usually in the hands or feet)
- Numbness or sensitivity to pain or temperature
- Extreme sensitivity to touch
- Sharp, shooting pain
- Poor balance or coordination (sometimes tripping when walking)
- Loss of reflexes
- Muscle weakness

It is important to know that there is not a specific treatment to cure neuropathy. Some things that can help with peripheral neuropathy include:

- Physical therapy to improve strength, balance, and coordination
- Occupational therapy to help with daily skills and coordination
- Sometimes orthotic devices and medication can also help improve symptoms

Things you can do at home:

- Avoid shoes that are too tight or too loose
- Keep your feet uncovered when you are in bed
- Massage

Lung health

Lung health can be affected by medications, radiation, and surgery to the chest area.

Symptoms include:

- Shortness of breath
- Coughing a lot
- Chest pain
- Getting tired easily (compared to before)

Some things that can help with lung health include:

- Do not vape, smoke, dip, or chew tobacco
- Avoid second-hand smoke (being around people who are smoking)
- Get regular physical exercise
- Avoid breathing toxic fumes from chemicals, solvents, and paints
- If you need help quitting smoking, some great resources include your family, friends, and your treatment team. They can help you start taking the steps to quit. Listed below are more support services:
 - American Cancer Society: 1-800-ACS-2345
 - American Heart Association: 1-800-242-8721
 - American Lung Association: 1-800-586-4872 and press 2
 - [SmokeFree.gov](https://www.smokefree.gov): Support, tips, tools, and advice to help you quit smoking

Heart problems

Heart problems, such as a change in your heart's ability to squeeze blood throughout the body, can happen from certain chemotherapy medications or radiation to the chest. Symptoms include:

- Shortness of breath
- Dizziness or lightheadedness
- Sweating
- Nausea
- Shortness of breath with chest pain
- Swollen feet or ankles

To be safe, if you were treated with a certain type of chemotherapy (anthracyclines) or chest radiation therapy, you should check with your healthcare provider before starting any exercise program. You will need regular screening if you have had any treatments that could affect your heart. You can help prevent any heart damage from getting worse by not smoking, having a healthy weight, eating a diet balanced with fruits and vegetables, and exercising.

Bone health

Bone health can get worse because of inactivity during treatment, as well as from cancer treatments themselves. You usually won't notice any symptoms of weak bones until they are very fragile and get fractures or break. This usually comes with pain or changes to the way you move your body (the way you walk, run, sit, or stand). Some things that can help with bone health include:

- Weight-bearing exercises (such as fast walking, dancing, aerobics, and jogging) help to develop healthy bones and keep them healthy.
- Higher-impact weight-bearing activities (such as hopping, jogging, and jumping rope) and resistance exercises (such as free weights and resistance bands) are also good for bone health. However, you should ask your doctor about the risk of doing these exercises based on the treatments you have received.
- A diet high in calcium and vitamin D is important to prevent bone breakdown. Diets rich in dairy products (milk, cheese, yogurt) and leafy green vegetables can help make sure you get enough calcium, which also helps bones. Your treatment team may recommend vitamin D supplements. Check with them before starting any supplements, as too much vitamin D is not good for the body.

Emotional Health & Well-being

What is emotional and mental health?

Mental health is overall wellness in how you think and feel, and what you do. Mental health is not about being happy all the time. It is normal to have lots of different emotions, including happiness, sadness, anger, anxiety, fear, joy, frustration, excitement... the list goes on and on! Every person copes or deals with big emotions or life challenges in different ways. Sometimes big emotions or life challenges can make it hard to do the things you want to do, or cause you to act in ways you normally wouldn't. Mental health concerns are really common, and there are many ways to improve mental health.

Emotional health services

What kinds of emotional and mental health services are available to me?

There are many providers and services at University of Michigan Health that can support your mental health. This includes child and family life specialists, psychiatrists, art and music therapists, psychologists, social workers, chaplains, palliative care, and pet therapy. Check with your treatment team or the AYA Oncology Program about these mental health providers and resources. If you would like to learn more about the supports mentioned, you can read more about each below:

Child and family life specialists (CLS): These are professionals who can help you cope with hospitalization and medical procedures. Child and family life specialists partner with the treatment team to help meet you or the children in your life's emotional, developmental, and cultural needs.

Psychiatrists: Psychiatrists are doctors with medical and psychiatric (focused on mental health and well-being) training. They can diagnose mental health conditions and prescribe and help with managing medications. Psychiatrists are also able to offer counseling and therapy.

Art therapists: Art therapists are professionals who help patients to express thoughts and feelings and learn to cope and problem-solve through the use of art. They are mental health providers that use creative expression to promote well-being. Art therapy is based on the belief that the creative process of art-making can help patients cope and adjust to illness, while also helping people express themselves and make meaning throughout their illness experience. Being creative can provide a safe and satisfying way to explore difficult experiences and emotions such as fear, sadness, frustration, and anxiety. Using the creative arts can also be a way to express gratitude, love, and hope while also:

- Helping you relax
- Processing overwhelming emotions
- Improving mood and self-esteem
- Developing coping skills
- Managing the effects of your treatment
- Increasing your self-awareness and mindfulness
- Improving communication
- Improving your quality of life

Music therapists: Music therapists are trained professionals and musicians who use music therapy, which is the use of music to meet a person’s needs for well-being. It is a field based on science and research. Using many different methods in both individual and group sessions, music therapy can support your care by:

- Helping you relax
- Expressing your thoughts and feelings
- Improving your quality of life
- Improving your memory
- Helping you sleep
- Improving your mood
- Managing pain
- Reducing anxiety and depression
- Creating memories for friends and family during your journey

Psychologists: These are professionals who provide mental, emotional, and social healthcare. Psychologists provide education, support, and counseling to address the **psychosocial** (mental, emotional, and social) needs you may have with cancer. Psychologists are mental health providers that can help with many different challenges, including:

- Coping with being sick or in the hospital
- Having a hard time taking medications
- Feeling down, depressed, worried, or anxious
- Coping with traumatic or scary experiences
- Talking with staff, family, and friends
- Problem solving in complex situations
- Goal setting
- Grief and end-of-life support
- Coping with pain, nausea, fatigue, and sleep problems

Social workers: These are professionals who provide counseling and find resources to help patients and families cope with issues related to illness. Social workers provide education, support, and counseling to address the psychosocial needs related to cancer. As members of the treatment team, social workers are familiar with the many kinds of stress that your family may experience. They are available to help you in the following ways:

- Partnering with your treatment team to provide services and care that represents your wishes, beliefs, and values
- Talking with the treatment team, you, and your support systems, and making sure everyone understands the treatment plan
- Connecting with you to provide supportive counseling and resources as needed
- Provide counseling during transitions (like when you return to your community, when you finish treatment, etc.)
- Share information about other health services
- Helping you cope with the effects of cancer and treatment
- Helping you with financial need (money) issues, including transportation, lodging, food, clothing, home utilities, medical equipment, medications and other costs

Spiritual care: Typically, spiritual care providers are trained chaplains who provide spiritual support throughout a person's illness in a medical setting.

Chaplains are trained clergy (religious leaders) who specialize in offering spiritual and emotional care and support to patients and their families. Chaplains listen to what is important to you, and they are respectful of differences in culture, religion, and lifestyles. Spiritual care can help you with counseling in many situations, such as:

- Coping with hard decisions, including decisions about your diagnosis and treatment
- Concerns you have with life's "why" questions ("Why am I here?")
- Feeling anxious or worried
- When you get bad news
- You are grieving (dealing with a death or loss)
- You want to explore life's deeper issues
- You need help connecting or reconnecting with the religious traditions of your past
- Parts of your spirituality or religion become important to you during your care
- Prayer or religious rituals become important to you during your care
- You have religious or spiritual questions during your care

Palliative care: Palliative care is comprehensive care that focuses on relieving pain, symptoms and stress for those who are living with a chronic, debilitating or serious illness such as cancer. The goal is to improve your quality of life, reduce hospitalizations, and help coordinate with other health care partners such as home care, hospice, rehabilitation, and alternative medicines. Palliative care can be appropriate at all stages of illness and is tailored to the needs of each patient and family. The palliative care team can help with:

- Assisting and establishing your goals
- Pain and symptom management
- Facilitating family meetings
- Providing education
- Improving communication with multiple care teams

Ask your medical team or the AYA Oncology Program for more information about mental health services available for adults through Rogel Cancer Center. More information can be found online at: RogelCancerCenter.org/support/managing-emotions.



For adolescents and young adults getting treatment through the Pediatric Oncology & Hematology Department, ask your medical team or the AYA Oncology Program about what mental health resources are available to you. More information can be found online at: MottChildren.org/ped-cancer.



Emotional health for cancer survivors

I've never met with an emotional health provider before - do you have any advice?

People meet with mental health providers for many different reasons throughout their lives. Everyone can use some help sometimes! There are mental health providers that are a part of your team to support your overall health and well-being. If you think that meeting with a mental health provider could be helpful in any way, please reach out!

How might cancer and its treatment affect my emotional health?

Being diagnosed with cancer and going through treatment can feel like an emotional rollercoaster. Because the mind and body are connected, being physically sick often affects emotions. You might feel shocked, afraid, angry, sad, embarrassed, lonely, hopeful, optimistic, determined, a different emotion, many emotions all at once, or you may not know how you feel. There is no right way to feel after a cancer diagnosis or during treatment.

What kinds of emotional reactions are common when finishing treatment?

You may find it hard to return to “normal” life after your treatment ends. It can be scary to try and go back to typical routines of school or work when you have been away from those activities to focus on your cancer treatment. It’s also very common to worry about the possibility of your cancer returning, especially when scans or follow-up appointments are coming up. You may even feel sad when treatment is ending, because of a loss of connection and community with your treatment team. Of course, there are also many exciting and hopeful things about finishing treatment that can be celebrated! Balancing good and bad feelings is one area that mental health providers can help you with.

Who can support my parents, partner, children, or other family members?

Your treatment team knows that a cancer diagnosis impacts your whole family. Team members from the social work or psychology departments can talk with your family and caregivers about any of their emotions, self-care, coping, and any day-to-day needs that they need support with. They can also provide mental health referrals for ongoing family support.

How do I talk to my loved ones about this diagnosis or my treatment?

Even though it is hard, being honest and direct about your experience can help others know what you need. Social work and psychology professionals can help you start conversations with your friends and family about important topics that will continue throughout your cancer experience. This includes talking about how you can balance your needs for support with your needs for independence. You may find that different strategies are needed for talking effectively with different caregivers, and social workers or psychologists can help with this too.

I have questions, fears, or worries about thoughts of death or dying. What supports are available to me?

These concerns are common, and they can be hard to talk about. Your medical providers, social workers, psychologist, and palliative care team can talk with you about death and dying. They can also help you start conversations about these issues with loved ones or medical providers. Team members from Social Work and Psychology can also provide support for grief and loss. Talk to your team if you are interested in these resources.

What do I do if I’m having a hard time talking with my providers or treatment team?

It is common to feel like you have too much or too little information. Social Work and Psychology team members can help you decide what you want to hear and who you want to hear it from. Hearing information from too many people can sometimes cause confusion, so you may find it helpful to work with your team to choose which providers you are most comfortable talking to. Social Work and Psychology can also help you talk clearly and effectively with your team about topics like treatment options and outcomes.

What can I do if I'm having a hard time keeping up with my treatment?

It can take up a lot of time and energy to manage daily medication routines and medical appointments. You may find that feelings of anxiety about pain or discomfort cause you to avoid doing things that are important for your health. The Psychology team can help you manage issues like forgetting to take your medication or feeling tired of cancer treatment by supporting you in making changes in your environment.

Emotional health resources: Coping with cancer

What are resources to learn more about coping with cancer?

<p>National Cancer Institute (NCI)</p> <ul style="list-style-type: none">• “Emotional Support for Young People with Cancer”• Link: cancer.gov/types/aya/support	
<p>National Cancer Institute (NCI)</p> <ul style="list-style-type: none">• “Coping with Cancer”• Link: cancer.gov/about-cancer/coping	
<p>American Society of Clinical Oncology (ASCO)</p> <ul style="list-style-type: none">• “Coping With Cancer”• Link: cancer.net/coping-with-cancer	
<p>Rogel Cancer Center</p> <ul style="list-style-type: none">• “Coping with Cancer Information Guide”• Link: RogelCancerCenter.org/files/coping-cancer-information-guide.pdf	

Are there resources that can help me cope with pain, nausea, and fatigue?

The Comfort Ability

- Website with resources for managing chronic (long-lasting) pain and staying active even when physical symptoms are bothering you
- Link: TheComfortAbility.com



Trails to Wellness

- Website with information on how to manage symptoms of depression and anxiety using Cognitive Behavioral Therapy (CBT) techniques
- Link: TrailsToWellness.org



The ABCD's of coping: This is a strategy that can help you with difficult medical experiences.

- **Activity:** When you are in the hospital and at home, staying active can help with your physical symptoms. Setting up routines with your caregivers can help when you are having a hard time staying active.
- **Breathing:** Diaphragmatic breathing (deep breathing from your belly) is a strategy that can help your body calm down, feel safe, and reduce your pain. The Psychology team can practice this breathing technique with you.
- **Counter-stimulation:** Pain and nausea are physical feelings that are processed in the brain. Using your other senses like sight, sound, taste, smell, and touch can redirect your brain and help you feel less bothered by uncomfortable or painful feelings.
- **Distraction:** Playing games, watching TV, or using a smartphone are all forms of distraction. Putting your attention on something other than your pain or discomfort can help make it easier to cope with.

I have trouble with anxiety about prescriptions and procedures - are there resources to help?

Meg Foundation

- Website with tools that can help you manage pain and anxiety about upcoming procedures
- Link: MegFoundationForPain.org



Michigan Medicine's Health Lab Blog

- “How to help kids swallow pills in 7 easy steps”
- Link: MichiganMedicine.org/health-lab/how-help-kids-swallow-pills-7-easy-steps



Are there resources that can teach me strategies to relax and manage anxiety?

BellyBio

- An iPhone app with biofeedback (using a device to give you feedback about how your body is functioning, so you can learn to make changes). It can help you learn how to breathe in a way that calms your anxiety.
- Link: apps.apple.com/us/app/bellybio-interactive-breathing/id353763955



Cardiograph

- A Google Play app with biofeedback that helps you learn how to control your heart rate through breathing
- Link: play.google.com/store/apps/details?id=com.macropinch.hydra.android&hl=en_US&gl=US



Meditation Studio

- A smartphone app with meditations for relaxation and sleep
- Link: MeditationStudioApp.com



UCLA Mindful Awareness Research Center

- Website with free guided meditations to help with anxiety, worries, and difficult physical feelings
- Link: UCLAHealth.org/programs/marc/free-guided-meditations/guided-meditations



10 Awesome GIFs for Calm Breathing

- Visual guides for breathing slowly and reducing anxiety
- Link: doyou.com/10-awesome-gifs-for-calm-breathing-59450/



Education & Career Support

Every person's needs during a cancer diagnosis are different. Your treatment team can help as you manage your education or your career, so that you can decide what these areas of your life will look like throughout the course of your treatment.

Depending on your health needs, you may be able to attend school or work in a way that is comfortable and safe for you. For college students, it is helpful to connect with the offices that support students with disabilities and chronic illness. They may be able to provide you with **accommodations** (getting technology or equipment you need, or making changes to your classroom and deadlines, so you can learn and work with your illness).

Social workers on your care team can also be a great resource to help you figure out what school plan works best for you. If you are an AYA, and you are working or starting your career, you can talk to your social worker. You may qualify for government or disability benefits to help support you when you cannot work. For AYAs with weakened immune systems, it is important to remember to keep your distance from people who have rashes, are coughing/sneezing, have a runny nose, or have had vomiting or diarrhea. If keeping your distance is not possible, you may need to consider going home.

High school education support

What are the recommendations for me if I am in high school?

Talk to your treatment team about going to school after you learn about your diagnosis and treatment. If going to school is not a safe option for you, talk to your medical social worker or hospital school liaison about schooling options that may work for you. Sometimes reducing the number of classes you're taking, taking virtual classes, or **homebound instruction** (having someone come teach you at home) can be options for you to continue to participate in school.

Homebound instruction services is a program designed to help students in K-12 public or charter schools who can't attend school due to a medical condition. This can help you keep up with your studies and continue school as far as possible with your medical condition. Each state's local or school district must provide homebound or hospitalized instructional services to an enrolled student if a doctor confirms they have a medical condition that requires them to be hospitalized or stay at home during regular school hours for 5 or more days in a row. Private or parochial schools are not required by law to provide this service, but they are often open to talking about other options to support the student's needs.

Think about getting a school advocate or point-person who can help share information with the school staff from you and your parent or legal guardian. It can also be helpful to create an e-mail group that includes you, your parents/caregivers, teachers, and counselors. This can help make sure communications between you all are fast, correct, and easy to access for everyone involved.

Support with education after high school

What resources are available to me if I am in college or a trade school?

It can be overwhelming to attend classes and manage school responsibilities during treatment. You can make the experience more manageable by talking to your academic advisor about your school's accommodations. They may offer you extra time for assessments or flexible scheduling to help you work through college.

Some other strategies that may help you continue working toward your degree include taking fewer classes, completing your coursework online, putting off starting college for a year after you've been accepted, or taking a leave of absence (time off). It can be hard dealing with feelings of missing out if you need to take a break from school to focus on your recovery. You may find it helpful to keep in touch with classmates, professors, and academic advisors, for you to feel connected.

Questions to ask your academic advisor:

- Are there support programs to help me keep up with schoolwork?
- Can I take a modified or lighter schedule?
- What are the rules and requirements for taking a leave of absence?
- Is there an aide or student that can take notes for me if I need to miss class?

Career support

What effects might cancer and cancer treatment have on my career?

Cancer treatment can affect your work and career, so it is important to talk with your treatment team when you're making decisions about whether you should work during this time. It's important that you have a complete understanding of your treatment plan, the possible side effects of treatment, and how much work you're able to do. Because of the Americans with Disabilities Act (ADA), your employer is required to make "reasonable accommodations" for you if your ability to work changes because of your treatment or side effects. Depending on your job, what counts as a reasonable accommodation may be different, but it could mean more breaks, using a seat or chair, flexible hours, or working from home or a different location.

If the Family Medical Leave Act applies to your workplace, you have the right to 12 weeks of unpaid time off a year, health insurance during your time off, and getting a job back when you return. This act also covers people who are caring for immediate family members that have a serious health condition.

Peer Support Programming

Peer Support

What is peer support?

Talking to someone who has had a similar experience as you (peer support) can help reduce the feelings of loneliness that come with a cancer diagnosis. If you are interested in 1-on-1 support, the Peer Support Program is an opportunity for adolescents and young adults to connect with other AYA's that have experienced a cancer diagnosis. The Peer Support Program offers the opportunity to become a mentor (someone experienced who can give support or advice) or a mentee (someone who is supported by a mentor).

How does peer support work?

Peer support can be a big part of coping with the challenges of the AYA cancer experience. Many healthcare systems know that there are unique emotional and social needs that happen during this time in your life, which can be an even greater challenge when dealing with cancer. Some parts of your life that may be affected include:

- Your identity and sexual development
- Struggles for autonomy (being independent and having the power to make your own decisions)
- Fertility preservation (how treatment might affect your ability to have children in the future)
- Changes or interruptions in schooling or at work
- Effects on your brain function
- Feeling alone or disconnected from peer and family support networks

Connecting with cancer peer supports can be an important tool for you to share your struggles, help others, and relate to others who share similar experiences.

What is the Peer Support Program at U-M Health?

AYA mentors share their own experiences and listen to patients and caregivers. They understand the effect a serious health issue can have on you. Participants of the Peer Support Program say this 1-on-1 communication with another patient or caregiver has been extremely helpful. All peer mentors are volunteers of U-M Health who have had a lot of training. This is what peer mentors do:

- Provide information, guidance, and emotional support to patients who have experienced a serious health issue like cancer

- Help patients deal with challenging issues and emotions
- Offer a group of peers to help those experiencing a health issue so that they won't feel alone
- Encourage patients to take part in their care




How can I sign up for peer support or become a patient mentor?

Talk with your medical team, social worker, psychologist or child and family life specialist to find out more information about peer support. Some information is below:

- **How do I become a peer mentor?** To become a peer mentor, patients must have been off treatment for at least 1 year. You must get trained through the Office of Patient Experience (OPE). Once you have talked with OPE, they will follow up with you about training sessions and approving you as a peer mentor.
- **How do I become a mentee?** Talk with your medical team, social worker, psychologist or child and family life specialist about your interest in finding a peer mentor. They will talk with you about the process and what you can expect.

What does peer support look like outside of U-M Health?

There are other organizations that work directly with you to connect you with peer support and mentors through their own matching process. Many of these organizations have national and regional locations that can help you find mentors and peer support close to you! Here are a few examples:

<p>Imerman Angels: Imerman Angels's provide comfort and understanding for all cancer fighters, survivors, and caregivers through peer mentor support.</p> <ul style="list-style-type: none"> • Link: ImermanAngels.org 	
<p>Cancer Support Community: CSC offers My LifeLine, which can help you connect virtually with family, friends, and others like you with the creation of a virtual website.</p> <ul style="list-style-type: none"> • Link: CancerSupportCommunity.org/mylifeline 	
<p>Be The Match: The Peer Connect Program at Be The Match connects transplant recipients and caregivers with someone who has been there and understands.</p> <ul style="list-style-type: none"> • Link: BeTheMatch.org/patients-and-families/support-for-you-and-your-family/peer-connect-program 	

Cancer Support Resources

What are cancer support resources?

There are many life changes and important questions that you may be considering during your cancer diagnosis, treatment, and survivorship (your time after surviving cancer) journey. To support you through these challenges, many organizations have resources that include help with finances, mental health resources, educational information, caregiver support, and wish-granting.

What are some AYA-specific cancer support resources?

Many organizations support AYAs with cancer and have created resources for you and your family. There are many cancer support resources, including:

- Support groups
- Wish organizations
- Scholarships
- Conferences and workshops
- Career services
- Mental health resources
- Retreats

What types of support groups and social organizations are there for AYAs?

The AYA oncology program at University of Michigan Health works to find and provide support resources for AYA's with a cancer diagnosis. There are many organizations that offer a wide range of support, including educational information as well as support groups, workshops, and conferences. Some of these groups are listed below:

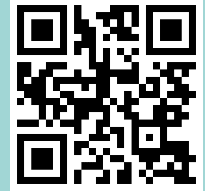
Stupid Cancer offers support by creating content for AYAs by AYAs. They help to empower everyone affected by AYA cancer by ending loneliness and building community. Stupid Cancer provides support for areas such as: Mental health, building a family, health and wellness, sex and relationships, caregiving, college and career, insurance and finances, health equity, and COVID-19.

- Link: StupidCancer.org



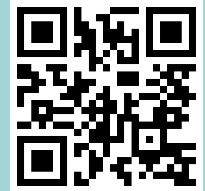
Elephants and Tea makes it their mission to help AYA patients, survivors, and caregivers know they are not alone in their fight with cancer. They have created a magazine written for and made by the AYA cancer community, weekly newsletters, as well as programs and events such as: Perkatory: Brewing Tough Conversations to Help Each Other Face Cancer, Weekly Happy Hour, and Spilling Tea with the G's (video-recorded interviews with people from the cancer community about the amazing work being done to support those living with cancer).

- Link: ElephantsAndTea.com



Imerman Angels: This organization works to provide comfort and understanding for all cancer fighters, survivors, and caregivers through a personalized, 1-on-1 connection with someone who has been there. Through their matching process, Imerman Angels can connect you to support that fits your needs.

- Link: ImermanAngels.org



Cancer Support Community: This organization provides information on different types of cancers, support resources, and education. The Cancer Support Community has many locations across the country and has a location in the Ann Arbor area. They provide people with cancer and their caregivers with virtual programs focused on support, education, and wellness, including support groups. Cancer Support Community also created a Cancer Support Hotline and a Live Web Chat for people looking for immediate support.

- Link: CancerSupportCommunity.org



Teen Cancer America works to change hospitals and create age-appropriate health care systems to increase the survival and improve the lives of AYAs. Teen Cancer America also provides many resources for AYAs and their caregivers. Some of their programs include: Cancer 101 (talks about the need for sharing the AYA cancer experience), Play it Back Music Program (connects AYAs with music industry professionals to give AYAs an opportunity to express themselves and heal through the art of music-making), and Cancer Rebellion (shares AYA stories and experiences).

- Link: TeenCancerAmerica.org



Cactus Cancer Society: An organization with a mission to provide a safe space where young adults with cancer can connect, cope, and thrive with one another in an online community through creativity and expression. Their vision is to end disconnection and loneliness for young adults with cancer. There are many programs and resources that you can connect with through Cactus Cancer Society’s website. These programs involve creative expression and can range from art workshops, to yoga, to creative writing.

- Link: CactusCancer.org



Cancer Dudes: Because there are fewer cancer resources designed specifically for men’s needs, this organization was created to provide education and resources for men to successfully move past their cancer experience. They offer the following: Courses (strategies and exercises to help you with the stress, anxiety, and hardship that comes after a cancer diagnosis), Connections (opportunity to connect with survivors and patients from around the country in their monthly online hangouts), and Wisdom (wisdom from survivors and other men who have overcome challenging situations).

- Link: CancerDudes.org



What are wish organizations?

Wish-granting organizations provide wishes to people who have a severe or life-threatening illness. Wishes often include travel, adventure, and mental, social, and emotional support. Some wish organizations require a referral from a member of your treatment team, and some organizations don’t. Check with the AYA Oncology Program to learn more! A list of some wish organizations is below:

Make-a-Wish: An organization that grants wishes for children who have been diagnosed with a life-threatening illness, who are between the ages of 2.5 and 18, and who have not received a wish from another wish-granting organization.

- Link: wish.org



• **The Rainbow Connection:** An organization whose mission is to make dreams come true for Michigan children with life-threatening medical conditions. Rainbow Connection also offers an enhancement program (fun program activities for children receiving wishes and their families), scholarships, and a special response program (designed to deal with unexpected and unplanned financial costs).

• Link: RainbowConnection.org



Wish Upon a Wedding: An organization that provides grants for weddings and vow renewals to couples with serious illness or life-altering health situations.

• Link: WishUponAWedding.org



The Jenna Kast Believe in Miracles Foundation: An organization whose mission is to help children in Michigan (ages 3-21) who have had a cancer recurrence or an ongoing medical condition. Believe in Miracles helps children who have already received a wish from a wish-granting organization, but who are still dealing their disease and could really use something to brighten their day.

• Link: BelieveInMiracles.org



Dream Foundation: The Dream Foundation changes lives, meet important needs, and provide inspiration, comfort, and closure at the end of life. Their wish granting has provided mental and emotional support to thousands of terminally ill adults and their families. Their work plays a. important role in the special end-of-life care that focuses on improving quality of life for patients and their families.

• Link: DreamFoundation.org



Dear Jack Foundation: From the Dear Jack Foundation, LifeList is a wish-granting program that offers hope and support to young adults who are currently getting treatment for a life-threatening illness. This program provides positive experiences to focus on during treatment and an opportunity to connect with a community of young adult patients, survivors, and advocates who have experienced similar things.

- Link: DearJackFoundation.org



Nikolas Ritschel Foundation: An organization that believes that fighting cancer is not only a physical battle but also an emotional battle that can be helped through loving support. Unfortunately, most pediatric cancer support programs end once that patient is 18, leaving a need for college-aged (18-24) young adults fighting cancer. However, this organization helps meet this need by working with these young folks.

- Link: NikolasRitschelFoundation.org



What retreats are available for patients and caregivers?

Some organizations offer workshops or retreats for patients and caregivers to improve the health and well-being of AYAs with cancer. Here is a listing of some of the retreats available to you:

Dear Jack Foundation: Hosted by the Dear Jack Foundation, the Breathe Now Wellness Retreats are open to young adult survivors (ages 21-39) and their partners who are 1-3 years after their last day of treatment. The Breathe Now Wellness Retreats use yoga, meditation, and psychosocial breakout sessions to help couples renew, learn, and grow as they live their lives together after cancer.

- Link: DearJackFoundation.org



Camp Mak-A-Dream: Camp Mak-A-Dream helps cancer survivors and their families to live with and beyond cancer through life-changing experiences in Montana. At the retreat, they strengthen life skills, improve their coping ability, and develop lasting relationships.

- Link: CampDream.org



First Descents: First Descents (FD) is a leader in outdoor experience programming. Through outdoor adventures, skills development, and local adventure communities, FD improves the long-term survivorship of young adults impacted by cancer and other serious health conditions.

- Link: FirstDescents.org



True North Treks: A nonprofit organization whose mission is to help young adults and caregivers affected by cancer to “find direction through connection.” They achieve their goals by taking groups on free backpacking and canoeing treks in beautiful wilderness locations. There, they can engage in important connections that are missing from typical cancer care. They also offer educational and supportive programming in cancer prevention and positive lifestyle behaviors to the public and those at increased cancer risk. Their programs include: wilderness trips, retreat-style experiences, training in mindfulness meditation and yoga (both in the field and online), and ongoing health promotion support to people who have gone through their programs.

- Link: TrueNorthTreks.org



What scholarships are available for AYAs with cancer?

There are many scholarship opportunities for AYAs going to college. These scholarships can help AYAs manage their financial needs in higher education. Most scholarships have strict deadlines, so make sure to check when applications open and close. Some scholarships are listed below:

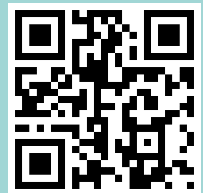
Cancer for College: Provides college scholarships and educational experiences to cancer survivors.

- Link: CancerForCollege.org



National Collegiate Cancer Foundation (NCCF): NCCF provides financial support to young adult survivors who are going to college throughout their treatment and beyond. Their General Scholarship Program supports young adult cancer survivors and current patients between the ages of 18-35. Their Legacy Scholarship Program is open to young adults ages 18-35 who have lost a parent or guardian to cancer.

- Link: CollegiateCancer.org



Cassie Hines Shoes Cancer Foundation (CHSCF): CHSCF has a travel support scholarship and grant that can help with the cost of attending a cancer-related camp or conference.

- Link: CassieHinesShoesCancer.org



Are there any career resources available for AYAs?

Your treatment team knows that cancer can affect your work life. There are resources that can help people with cancer deal with working during and after cancer treatment.

Cancer and Careers: An organization that offers important information about legal and financial aspects of life during cancer care, as well as information about returning to work after cancer. They offer free resume review services, free career counseling, access to a job search toolkit (that is free to download), and professional development grants.

- Link: CancerAndCareers.org/en



What conferences are there for patients and caregivers?

Conferences are meetings for healthcare professionals, patients, and caregivers who want to improve the medical and emotional care for young people diagnosed with cancer.

Texas AYA Oncology Conference: A conference that meets once a year for 3-4 days. It is offered in-person and virtual to talk about topics relating to the AYA cancer experience.

- Link: txayaoc.com



Adolescent and Young Adult Cancer Congress: This event is the world's most significant gathering of medical professionals and advocates in AYA cancer care! This congress will offer clinical, allied health and social care professionals, along with AYA focused patient advocates a space to learn from leading international experts, share research and care practices, and connect to a worldwide network that is focused on improving cancer care and outcomes for this unique population of young people.

- Link: AYAGlobalCancerCongress.org



CancerCon: Brought to you by Stupid Cancer, every year, hundreds of adolescents and young adults affected by cancer gather at CancerCon for a life-changing weekend. CancerCon brings together hundreds of patients, survivors, advocates and health professionals to learn, share, and build community. This conference is available in-person and online.

- Link: StupidCancer.org/CancerCon



How can I start my search and use these resources?

Starting the search for AYA-specific resources can feel overwhelming, and it can take a lot of time. Talking with the AYA Oncology Program or a member of your treatment team like your social worker can be a good start in your search. Ask questions like:

- What are AYA-specific resources I can use for financial help, mental health resources, peer support, and caregiver support?
- How can I connect with these specific resources?

Your social worker can help connect you and an organization, so be sure to talk to them about your questions and needs.

This above list of AYA resources is not complete. There are always new organizations and resources being created to support AYAs experiencing cancer. To learn about the latest supports for AYAs, stay connected! Social media is a great tool to use to find AYA specific resources. Follow social media pages and accounts that you find interesting and are useful for you.

Need more information? Help is available!

- Visit careguides.med.umich.edu for resources from medical professionals. The site includes videos, websites, and handouts created or approved by University of Michigan Health clinicians.
- Email UMHS Patient Education at umhs-patienteduaction@med.umich.edu and request a consultation with a health educator if you need help with any patient materials that have been shared with you.

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