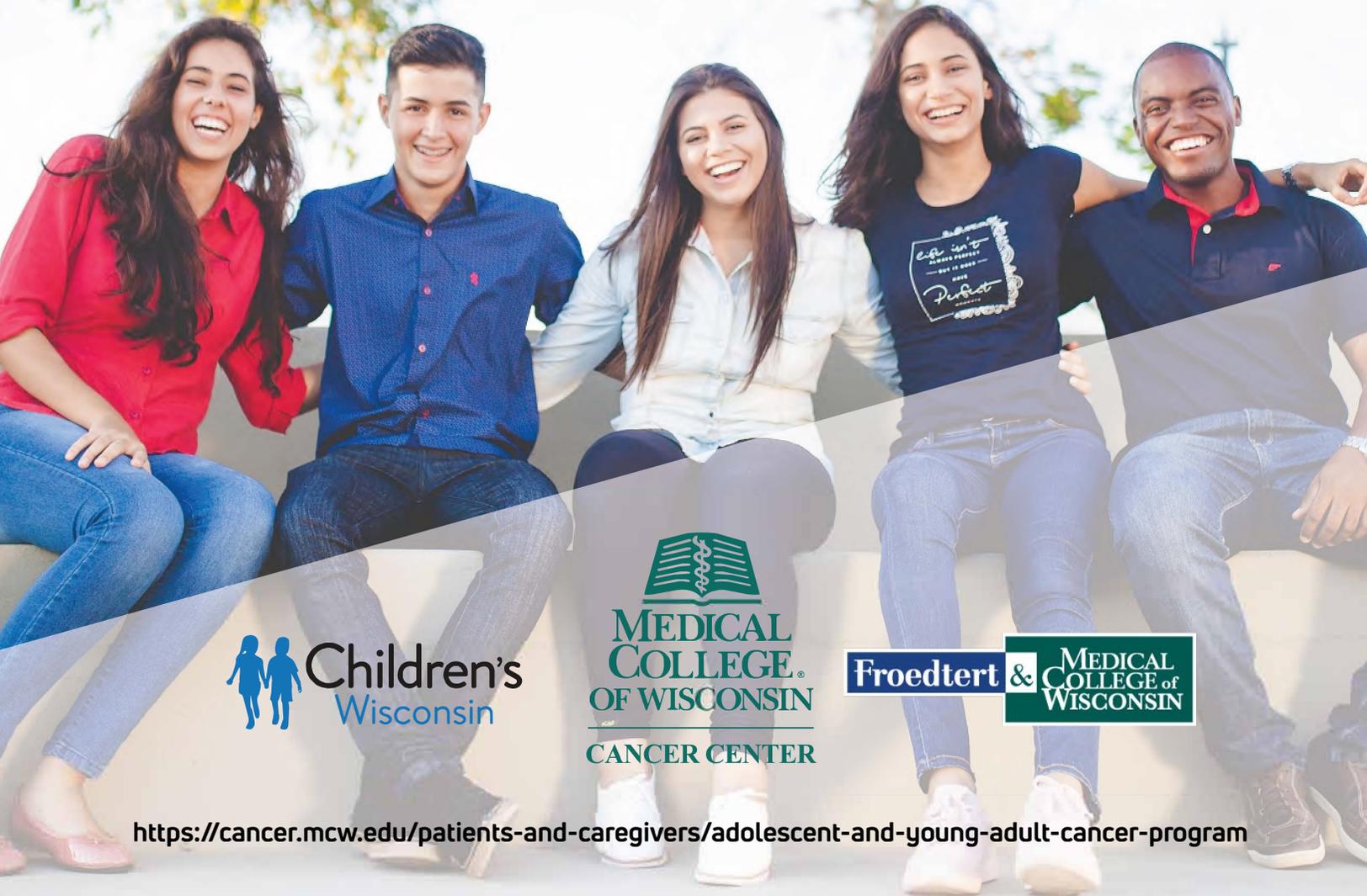




adolescent +  
young adult  
cancer program



Children's  
Wisconsin



MEDICAL  
COLLEGE  
OF WISCONSIN

CANCER CENTER

Froedtert &

MEDICAL  
COLLEGE of  
WISCONSIN

<https://cancer.mcw.edu/patients-and-caregivers/adolescent-and-young-adult-cancer-program>



  
**MEDICAL  
COLLEGE  
OF WISCONSIN**



# ADOLESCENT & YOUNG ADULT CANCER

Teen years and young adulthood are filled with exciting promises and new challenges, like starting a job, looking forward to college, dating, raising a child or planning for a family. A cancer diagnosis is never part of the plan.

Still, you're not alone. There's a community of people who are patients, survivors, caregivers, researchers, navigators and medical experts who can help you. This is why the Froedtert & the Medical College of Wisconsin Cancer Network, and Children's Wisconsin created programming and tools to help you navigate your cancer experience.



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### TIPS FOR YOUR CANCER EXPERIENCE



### ADDITIONAL RESOURCES



**I'm too young for cancer.**

**It's true. Often, older people get cancer. You are not old, and you still have cancer. That doesn't mean you should receive treatment the same way as an older person might.**

**The Froedtert & the Medical College of Wisconsin health network and Children's Wisconsin have built an Adolescent and Young Adults (AYA) Cancer Program made specifically for teens and young adults. We've worked with AYAs and their treatment teams to create support groups, educational programming, advocacy resources and guidance to meet your unique needs.**

**We have assembled this book as a general guide to resources available at our hospitals and in the community.**

**We encourage you to ask questions and use all the resources available here to navigate your cancer experience. Remember it's okay to lean on your care team, family and friends for support during the process.**

# OUR PROGRAM

Our AYA Cancer Program will provide you quality and supportive care resources from diagnosis through treatment and beyond with a focus on:

- Clinical trial education
- Sexual health considerations
- Fertility preservation counseling
- Health insurance/financial counseling
- Psychosocial support and spiritual care
- Transition to post treatment survivorship services



## YOUR CANCER EXPERIENCE



We know this isn't where you thought you would be at this moment in your life, but we are here to help.

Your first step is understanding your diagnosis and treatment plan. Ask questions and have conversations with your health care team and loved ones. We will support you along the way during your entire cancer experience.

# EDUCATE

## KNOW YOUR OPTIONS

Dealing with cancer is tough for anyone, but it can be especially difficult for adolescents and young adults. Take charge of your health and your health care needs as much as you can.

The person who speaks best for you is you. Speak openly with your care team about any questions or concerns. This will get you the best care possible. You are the most important person in the room.

First try to understand as much as you can about your diagnosis and treatment options. Explore this booklet and other resources from your treatment team to learn more.

If you need assistance or have questions, please contact our AYA Cancer Program [aya@mcw.edu](mailto:aya@mcw.edu) or speak with your care team.





MCW  
DIVERSITY SUMMER  
HEALTH-RELATED  
RESEARCH EDUCATION PROGRAM  
(DSHREP)

# CLINICAL TRIALS

A clinical trial provides eligible patients with the opportunity to receive additional treatment using the latest medicine, technology and approaches available in cancer care. Some clinical trials involve treatment, while others are interventional and aim to improve quality of life and care for cancer survivors.

Clinical trials are not random experiments. They are highly controlled studies designated only for eligible patients that aim to improve cancer treatment outcomes. While not guaranteed, every breakthrough in available cancer treatments started as a clinical trial.

The National Cancer Institute provides accurate information and research about cancer, cancer treatment, and supportive resources for adolescents and young adults with cancer. Your care team can help you determine which clinical trials are available based on your treatment plan and eligibility.

Your contribution as a clinical trial participant helps cancer researchers and your care team gain potentially life-saving knowledge about how to treat your type of cancer.

You might be eligible for different clinical trials. Ask your care team for help to determine your options or consider exploring the clinical trial websites below.

1. Children's Wisconsin:

[childrenswi.org/medical-care/  
macc-fund-center/clinical-trials/  
clinical-trials-for-pediatric-cancers](https://childrenswi.org/medical-care/macc-fund-center/clinical-trials/clinical-trials-for-pediatric-cancers)

2. Froedtert & the Medical College of Wisconsin Cancer Network:

[froedtert.com/clinicaltrials](https://froedtert.com/clinicaltrials)

3. ClinicalTrials.gov:

[clinicaltrials.gov/](https://clinicaltrials.gov/)

## CONSIDER A SECOND OPINION

A second opinion is when a doctor other than your primary one reviews your medical chart and test results to give you a diagnosis and treatment recommendation. A second doctor's opinion may turn out to be the same as your primary or it may suggest a different approach or include additional recommendations. By seeking a second opinion, you will become more informed about all of your available treatment options to help you make the best decision for you.

# SEXUAL HEALTH DURING AND AFTER CANCER TREATMENT

Sexual health, sexuality and intimacy can be impacted by cancer treatment. Having concerns about any or all of these topics is completely normal and ranks high on the list of most common concerns for adolescents and young adults with cancer.

Write down your questions ahead of time. If you feel nervous, practice your questions out loud. If it would help, bring someone along to support you.

*A few examples to get the conversation started:*

*"I have a personal question I would like to talk to you about..."*

*"I have symptoms I'd like to talk about that are affecting my sexual health...."*



## FREQUENTLY DISCUSSED TOPICS

Body image/self-image:

- Physical body changes
- Changes in menstrual cycle
- Pain, discomfort or physical limitations
- Fatigue
- Sadness or depression
- Hormone changes

Dating and relationships:

- Intimacy
- Vaginal dryness
- Getting or maintaining an erection
- Libido (changes in desire or interest)
- Safe sex/birth control

# FERTILITY TREATMENT

Families come in all shapes and sizes and cancer survivors become parents in many different ways. The pathway to parenthood may include natural conception, use of one's own preserved eggs or sperm, use of egg or sperm donors, use of surrogates, and adoption.



Cancer treatments, including radiation and chemotherapy, can impact fertility. Fertility is defined as the ability to conceive (or make) a baby. There are options available to women and men to increase the chance of becoming pregnant or fathering a child naturally after cancer treatment.

These options work best when they are done before cancer treatment starts. The first step is to talk to your health care team and share your thoughts about your future.

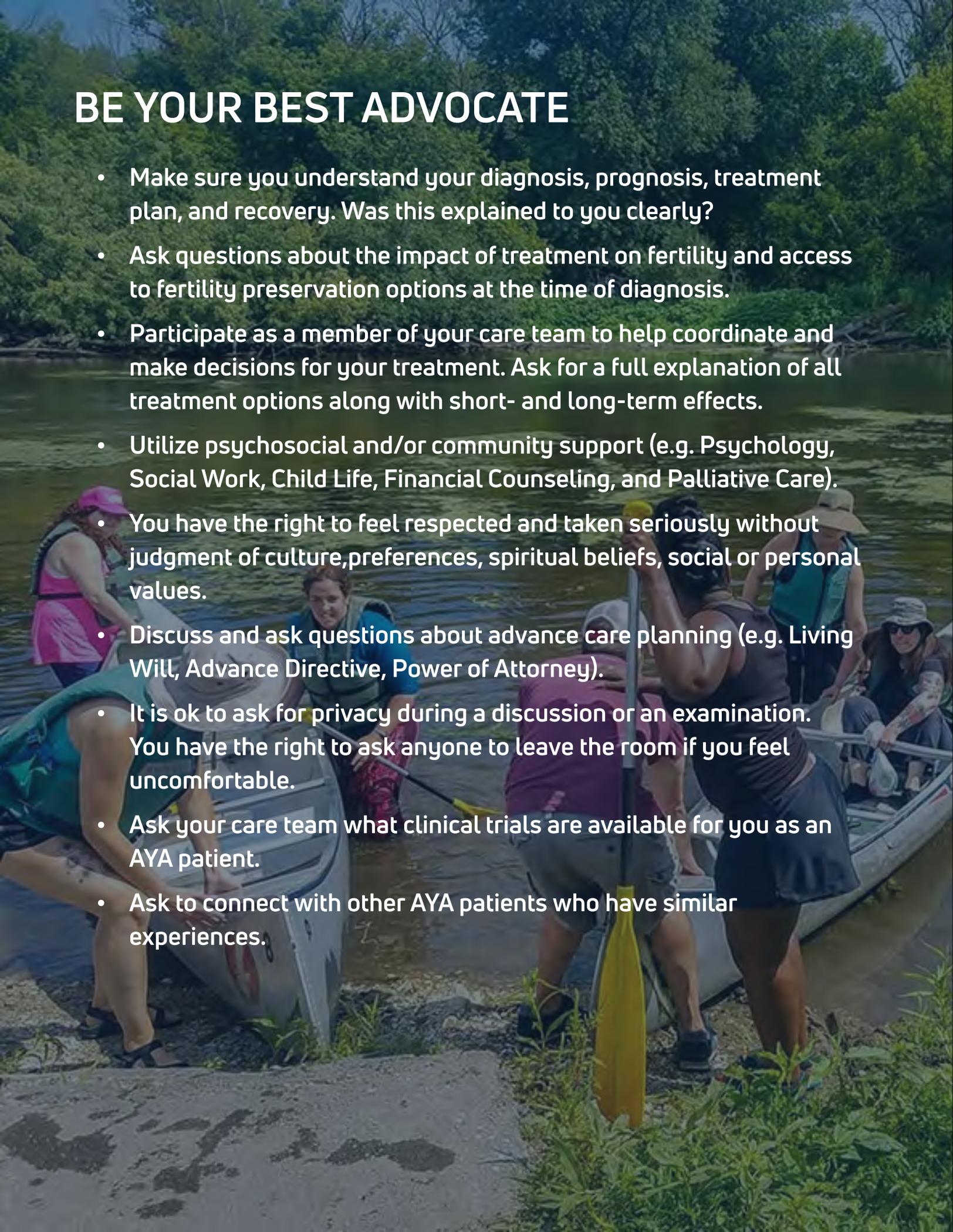
## Resources

We have resources, educational materials, and videos that can help you make the decisions that are best for you. More information about fertility options are available at [froedtert.com/fertility/preserving-fertility](https://froedtert.com/fertility/preserving-fertility) and [childrenswi.org/fertility-navigation](https://childrenswi.org/fertility-navigation). Patients at Children's Wisconsin can utilize the Fertility Navigation Program. A Fertility Nurse Navigator is available to talk with you about fertility risk and the options you may have for fertility preservation (protecting or saving your eggs or sperm). Ask your health care team to connect you.

Find more answers to your cancer-related fertility questions at [savemyfertility.org](https://savemyfertility.org)

# BE YOUR BEST ADVOCATE

- Make sure you understand your diagnosis, prognosis, treatment plan, and recovery. Was this explained to you clearly?
- Ask questions about the impact of treatment on fertility and access to fertility preservation options at the time of diagnosis.
- Participate as a member of your care team to help coordinate and make decisions for your treatment. Ask for a full explanation of all treatment options along with short- and long-term effects.
- Utilize psychosocial and/or community support (e.g. Psychology, Social Work, Child Life, Financial Counseling, and Palliative Care).
- You have the right to feel respected and taken seriously without judgment of culture, preferences, spiritual beliefs, social or personal values.
- Discuss and ask questions about advance care planning (e.g. Living Will, Advance Directive, Power of Attorney).
- It is ok to ask for privacy during a discussion or an examination. You have the right to ask anyone to leave the room if you feel uncomfortable.
- Ask your care team what clinical trials are available for you as an AYA patient.
- Ask to connect with other AYA patients who have similar experiences.



# ENCOURAGE

## YOU ARE NOT ALONE

Cancer as an AYA is different than cancer as an older person or a young child. We understand that it can be isolating and overwhelming. Our resources are built to support you throughout your entire cancer experience. We encourage you to talk about your treatment, feelings, and needs with your health care providers and support network. And we encourage you to connect with other AYAs who know what it's like to go through this experience at your age.



# HOSPITAL BASED RESOURCES

## **AYA and Cancer Caregivers Support Groups**

Support groups are open to anyone caring for a loved one diagnosed with any type of cancer. Groups focus on the importance of the caregiver's emotional health with opportunity for discussion and sharing of experiences, communication of feelings, relaxation, and stress relief. For more information about support groups available through the Froedtert & the Medical College of Wisconsin Cancer Network, Children's Wisconsin and our partners, see our websites:

[www.froedtert.com/classes](http://www.froedtert.com/classes)

## **Teen Activities**

FREE social activities are available outside of the hospital for Children's Wisconsin patients, ages 12-17, to connect with other teen cancer patients and survivors. Additionally, adolescents who are hospitalized have access to Children's Wisconsin's Teen Lounge for additional social programming.

[childrenswi.org/macc-fund-center-teen-events](http://childrenswi.org/macc-fund-center-teen-events)

## **The Young Adult Oncology Group**

The Young Adult Oncology Group [childrenswi.org/YAOG](http://childrenswi.org/YAOG) provides social opportunities for adolescents and young adults (ages 18-39) to share experiences and participate in social and recreational gatherings. Activities include cooking classes, rock climbing, game nights, hiking, sporting events, and more! AYA patients can request to join the Facebook group by searching for "YAOG Midwest Wisconsin". To join the YAOG email list send a message to [aya@mcw.edu](mailto:aya@mcw.edu).

# NATIONAL RESOURCES

## **Imerman Angels**

Imerman Angels connects those fighting cancer with a survivor of the same cancer. The program also connects caregivers. <https://imermanangels.org/>

# EMPOWER

## HOLISTIC HEALTH AND WELLNESS

We offer different programs and services to help empower you on your cancer experience through emotional, mental, and physical well-being. Our goal is to incorporate wellness for your full body. There are opportunities at the hospital to help you feel your best. We also work with community organizations to bring wellness programming for patients.



# HOSPITAL BASED SERVICES

## **Nutrition Services**

Many people benefit from the help of a dietitian who can provide healthy eating and nutrition guidance during your cancer treatment. Your doctor may suggest you see a dietitian as part of your cancer treatment plan, or you may request a referral or consult by talking to a member of your care team.

## **Physical and Occupational Therapy Services (Rehab Services)**

Occupational and physical therapists are available to help you with cancer-related fatigue, decreased strength, decreased endurance and mobility, balance problems, chemotherapy induced neuropathy and lymphedema management. If you have questions, talk with your physician about an order to see an occupational or physical therapist.

## **Small Stones Wellness Center**

The Small Stones Wellness Center, [froedtert.com/smallstones](https://froedtert.com/smallstones) provides wig, skin care, make-up consultation, health and wellness classes, and mind-body treatments for cancer patients and survivors. Services are offered at Froedtert & MCW locations in Wauwatosa, West Bend and Oak Creek.



# COMMUNITY BASED SERVICES

## Healing Haven of Wisconsin

Healing Haven of Wisconsin is a private clinic designed to guide you through medical hair loss by helping you rebuild your look, style and confidence in a one-on-one setting or with your support team. Healing Haven of Wisconsin partners with Children's Wisconsin to bring education classes about recreating identity after a medical diagnosis to AYAs. Patients learn tips and tricks about skin care, makeup, nails, hair loss and more. Check with your care team about joining a class. [www.healinghavenofwi.com/](http://www.healinghavenofwi.com/)

## Livestrong® at the YMCA

A researched-based program designed to help adult cancer survivors (18 years and older) reclaim their health and begin their journey toward recovery.

[gwcymca.org/LIVESTRONG-at-the-YMCA](http://gwcymca.org/LIVESTRONG-at-the-YMCA). Regular participation in physical activity is important for the following reasons:

- Increases quality of life and survivorship
- Improves your mood
- Increases your sense of wellness in your body
- Increases muscle strength and tone
- Improves your endurance
- Improves your ability to complete your activities in daily life
- Helps you control your weight
- Improves circulation
- Decreases fatigue



# CONNECT

## CONNECT WITH THE SUPPORT YOU NEED

Your life before diagnosis and your life after treatment are the same and yet radically different. Let us help you find a way to express yourself during and after treatment. Whether you need to talk about your feelings and what you are going through or just want to draw it out.

A diagnosis of cancer can be frightening for patients and their families. We offer psychosocial services at Children's Wisconsin and all Froedtert & MCW locations to help support you through this time. The next page explains the psychosocial support you can connect with at your hospital.



# GET SUPPORT

## **Spiritual care**

Chaplains provide spiritual and emotional support for patients and families of all faith traditions. They are helpful even for families who do not have a faith tradition by assisting families during hospital stays.

## **Therapy dogs**

Trained, certified therapy dogs offer comfort to help reduce stress in the hospital by creating a distraction from the illness and hospital procedures.

## **Social work**

Social workers meet with patients and families to assess needs and connect them to community resources. A social worker can help with a range of social, emotional, financial, and practical needs related to the cancer diagnosis and treatment including work, school, insurance, transportation, and advance care planning.

## **Child life**

Child life specialists teach healthy coping skills for patients and their families, including the siblings or children of AYA patients to build understanding and preparation for medical procedures.

## **Mental/Behavioral Health**

Provide supportive counseling and teach patients and families ways to cope with cancer-related distress.

## **Palliative care**

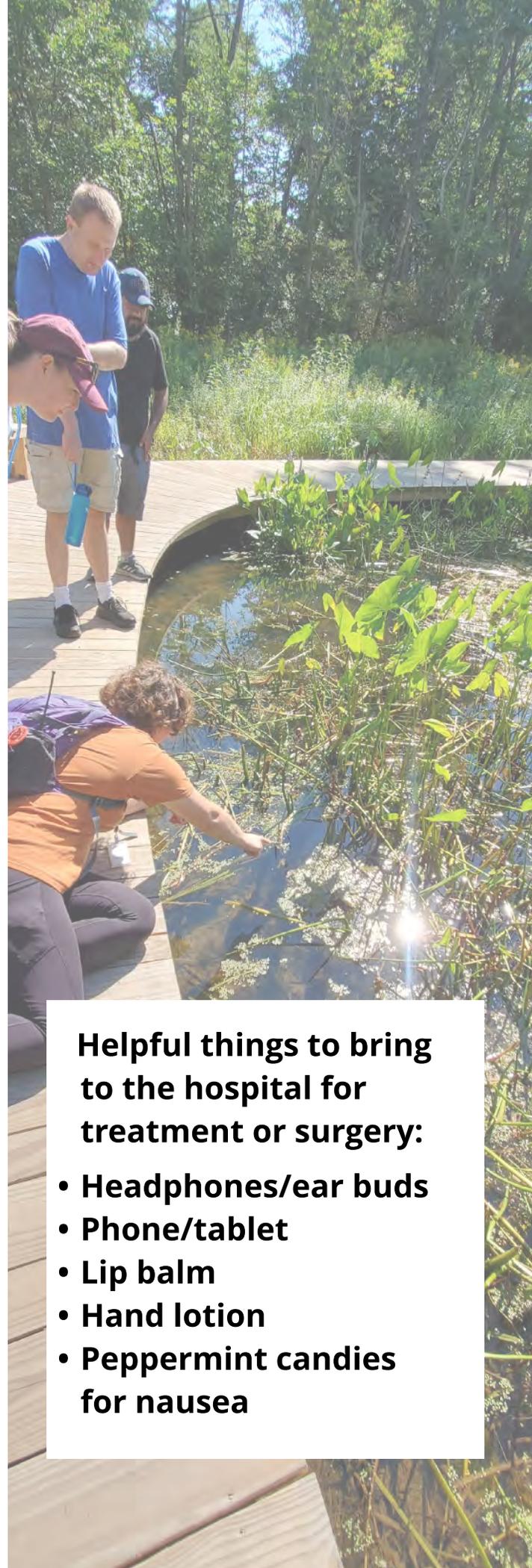
Focuses on quality of life during cancer treatment. Palliative Care services include emotional support and help with symptom management. They can also help with end-of-life care and bereavement.

## **Art therapy**

Creative expression through art Therapy sessions can address the mental health needs of patients undergoing cancer care.

# TIPS FROM THOSE WHO WALKED IT

- Look for small victories in every day.
- Decorate your hospital room to make it feel like home.
- Take advantage of your good days. Get outside when you can. Continue to do the things you enjoy.
- Find ways to express yourself.
- Be prepared to binge watch your favorite shows. Bring your laptop or tablet with you to the hospital.
- Build relationships with your care team. They will be your biggest advocates.
- Reach out to other young cancer survivors.
- Know it's okay to stay in bed for the day.
- Bring someone with you to your appointments.
- You might lose some, all or none of your hair. It's your choice to wear a wig, hat, scarf, or just be bald. Bald is beautiful too.
- Let your emotions out. Don't hold them in.
- It's okay to show emotion.
- Don't feel you need to be the "strong one" so that (insert person here) doesn't worry.
- Don't be afraid to ask for and accept help.
- Go to therapy. This is a life-changing situation. You may need help processing your feelings.
- Reach out to other young cancer survivors. It's helpful to find others who are going through or have gone through similar experiences.



## **Helpful things to bring to the hospital for treatment or surgery:**

- **Headphones/ear buds**
- **Phone/tablet**
- **Lip balm**
- **Hand lotion**
- **Peppermint candies for nausea**

# ADDITIONAL RESOURCES

## ADVENTURE PROGRAMS

### Camp Koru

A free outdoor adventure camp that helps young adult cancer survivors find healing and renewal beyond cancer.

### Camp Make-A-Dream

Camp in Montana provides medically-supervised, cost-free experience for children, AYA, and families affected by cancer.

### Camp One Step

Provides free programs serving kids with cancer (up to age 19), siblings and their families, bringing them happiness, joy, connection, and support.

### Epic Experience

Empowers cancer patients and survivors through a free week-long outdoor adventures in the Colorado Rocky Mountains.

### First Descents

Provides life-changing outdoor adventures for young adults (ages 18 - 39) impacted by cancer and other serious health conditions.

### True North Treks

Empower young adults and caregivers affected by cancer to "find direction through connection." Focus on the connection with nature, peers and oneself through free backpacking and canoeing treks.

# ADVOCACY/EDUCATION/RESEARCH

## The American Cancer Society

Focused on research to improve treatments, advocacy for lifesaving policy changes, health promotion for cancer prevention, and education to support people in every community touched by cancer. ACS has education related to healthy lifestyle, sexuality, fertility, disease specific information, treatment and survivorship education.

## Look Good Feel Better

A non-medical service program that teaches beauty techniques to people with cancer to help them manage the appearance-related side effects of cancer treatment. The program includes lessons on skin and nail care, cosmetics, wigs and turbans, accessories and styling, helping people with cancer to find some normalcy in a life that is by no means normal. Live! Virtual Workshops provide a safe, convenient way to experience Look Good Feel Better from home.

## Teen Cancer America

Works to improve the experience, outcomes, and survival of teens and young adults with cancer by providing facilities and programs designed especially for them in hospitals throughout the USA.

# CAREER

## Cancer and Careers

Empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events. Free services include a comprehensive website, legal and insurance information, career coaching, resume review, professional development micro-grants, and national events and workshops.

## Job Accommodations Network

Free, expert and confidential guidance on workplace and employment issues. Wisconsin Department of Workforce Development: Vocational Rehabilitation List of top 10 things you should know.

# COMMUNICATION & SUPPORT MANAGEMENT

## [CaringBridge](#)

A personal health journal, rallying friends and family during any type of health experience. Building bridges and communication to help friends and family stay connected and organize support throughout your experience.

## [Mylifeline.org](#)

MyLifeLine exists to easily connect cancer patients and caregivers with friends and family in order to reduce stress, anxiety and isolation. By creating your own private website you can document your journey, and receive social, emotional, and practical support from friends and family throughout the treatment process and beyond.

# DISEASE SPECIFIC

## [BMT InfoNet](#)

Leading advocacy program for BMT and CAR T-cell Therapy patients. Pioneered a vast array of services and educational programs to help patients make critical decisions throughout their transplant.

## [The Leukemia and Lymphoma Society](#)

The mission of the LLS is to cure leukemia, lymphoma, Hodgkin disease and myeloma and improve the quality of life of patients and families. The LLS provides education, support and financial support.

## [Sarcoma Foundation of America](#)

Advocates for sarcoma patients by funding research and by increasing awareness about the disease. The organization raises money to privately fund grants for sarcoma researchers and conducts education and advocacy efforts on behalf of sarcoma patients.

# FINANCIAL

## The Sam Fund/Expect Miracles Foundation

Supports young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. One way is by providing financial assistance in the form of grants to young adult cancer survivors.

## Triage Cancer

Provides education on practical and legal issues that may impact individuals diagnosed with cancer and their caregivers. Through free in-person and online educational events, materials, videos and state-specific resources focused on expert content related to work, insurance, disability benefits, finances, estate planning, medical decision making, and more. Free one-on-one help is available too.

## Tricia's Troops Cancer Connection

Provides financial assistance, service coordination and supportive care to cancer patients throughout Southeast Wisconsin. Focuses on the daily living challenges and out-of-pocket expenses and offers free services and supplies to local cancer fighters

# SCHOLARSHIPS

## Cancer scholarship opportunities

Trusted programs for educational funding, support and related resources.

[childrenswi.org/maccfundcenter/scholarships](http://childrenswi.org/maccfundcenter/scholarships)

# SUPPORT GROUPS

## Cactus Cancer Society

First and only virtual community built by, and for young adults facing cancer that provides age-appropriate support programs and resources focused on coping through creative expression and connection - all in the pursuit of making survivorship support available and accessible to those who need it, no matter who or where they are.

## Elephants & Tea

Helps AYA patients, survivors and caregivers know they are not alone in their fight with cancer. The elephant in the room is cancer. Tea is the relief conversation provides. The only magazine written for and by AYA cancer community members telling their stories in their own words. Elephant & Tea website showcases AYA programming across multiple organizations.

## Gilda's Club Madison

Provides free emotional support, cancer education, and wellness activities to children and adults impacted by any kind of cancer and those who care for them. Offers special programs just for AYAs. Open to anyone in Wisconsin (virtual & in-person).

## Stupid Cancer

National nonprofit organization whose mission is to help empower everyone affected by AYA cancer by ending isolation and building community. Our goal is to make cancer suck less by connecting AYAs to age-appropriate programs and resources, like CancerCon and our social Meetups.

## Ulman Foundation

Dedicated to changing lives by creating a community of support for young adults and their loved ones impacted by cancer.

# **SURVIVOR & CAREGIVER RETREATS**

## Dear Jack Foundation

Provides impactful programming that directly benefits AYAs diagnosed with cancer in order to improve quality of life and create positive health outcomes from treatment to survivorship for patients and their families.



**adolescent +  
young adult  
cancer program**

Visit the Adolescent and Young Adult Cancer Program Websites

<https://cancer.mcw.edu/patients-and-caregivers/adolescent-and-young-adult-cancer-program>

<https://childrenswi.org/medical-care/macc-fund-center/programs-and-services/oncology-program/adolescent-and-young-adult-cancer-program>

[www.froedtert.com/cancer/adolescent-and-young-adult-cancer-aya](http://www.froedtert.com/cancer/adolescent-and-young-adult-cancer-aya)

For more information, email: [aya@mcw.edu](mailto:aya@mcw.edu)

