Adolescence and young adulthood are often filled with exciting possibilities as well as challenges. This stage brings all the beginnings of life as some may be attending school, starting careers, dating or in relationships, or planning for or raising children.

A cancer diagnosis does not fit into any of this and can cause significant disruption. Recognition of your age group’s unique needs has led Froedtert & the Medical College of Wisconsin and Children’s Hospital of Wisconsin to collaborate in the development of specific services that focus on adolescents and young adults diagnosed with cancer.

I’m too young for cancer.

Statistically, you are correct. Statistically, older people get cancer more frequently than younger people. Older people get cancer and older people get treatment for cancer. You are not old, but you still have cancer. You shouldn’t be getting the same treatments as everyone else.

In our Adolescent and Young Adult cancer program you won’t. Treatment in our AYA program is designed for you - an adolescent or young adult. We have worked with people your age to develop these resources. You have different needs and different things happening in your body. The focus on your treatment should be different too. Here, it is.

You are not the first to walk this path. We have assembled this book as a general guide of resources available here and elsewhere and in the physical and digital realms.

You are not alone.

But, it can be lonely on this journey, so ask questions and take advantage of all the resources that are here to support and help you.

Let’s take the next step.
Your Journey
We know this isn’t where you thought you would be landing at this moment in your life.

Your first step is understanding your diagnosis and treatment plan and having conversations with your health care team and loved ones.

As your cancer journey unfolds we will support you along the way.

Our Program
Our AYA cancer program will provide you quality and supportive care resources from diagnosis through survivorship, with focus on:

- Clinical trial education;
- Fertility preservation counseling;
- Health insurance/financial counseling;
- Psychosocial support and spiritual care;
- Transition to survivorship services

The path begins by identifying your individual needs and those of your family and the resources available through:

Educating you and your family about your cancer diagnosis and treatment options that are available to you including the opportunity to participate in clinical trials.

Encouraging effective communication with your health care providers, family, friends, community and others in your support network.

Empowering you to take an active role in your cancer treatment and supporting you as you face challenges.

Connecting you with emotional, financial, and wellness resources to meet your specific needs.
Educating

**Clinical Trials**

What is a clinical trial? They are not what you may think.

It sounds like some crazy medical research - the kind where you are the guinea pig. You are here for treatment not so someone can experiment on you, right? Hold on a minute.

Clinical trials are not random experiments. They are highly controlled studies and every breakthrough has come from clinical trials. Where do you think the treatment we are using right now came from? That's right. A clinical trial.

You know the latest song. You know the latest tech trend. Why not be a part of the latest treatment? A clinical trial gives you the opportunity to receive the newest technology.

We will help you to determine what clinical trials are available and which ones you may be eligible for joining. Be on the cutting edge of medicine.

Find your best path

Dealing with cancer is tough for anyone, but it can be especially difficult for adolescents and young adults.

As a young person with cancer you may face different challenges throughout your treatment and into survivorship that require individualized care. You are encouraged to advocate for yourself and take charge of your health and your health care needs. This may seem obvious, but the person who speaks best for you is you. Being an assertive advocate for yourself means speaking boldly and confidently for your own cause.

It is encouraged that you speak openly with your care team about any questions or concerns in order to receive the best care possible.

Explore the clinical trial portals on this page and the next to help understand the options available to you.

If you need assistance or have questions, please contact our AYA Program or speak with your care team.

**Where to Look for Clinical Trials at Our Hospitals**

When searching for clinical trials remember to try various keywords that connect to your cancer as well as other specific elements such as 'AYA' and 'young adult' or "adolescent". There can be a lot of confusing terminology and aspects of the process - don't be discouraged and remember it is ok to ask for help.

Steps to follow in your search:

1. Understand your cancer diagnosis.
2. Talk to your health care provider and care team.
3. Ask your doctor about available clinical trials and begin your search together.
4. Talk to your doctor about your eligibility and risks.
5. Take a closer look at what the trial is all about.
6. Keep asking questions.
Fertility
Before, During, After Treatment

Will I be able to be a parent?
There are nearly 500,000 cancer survivors of reproductive age in the United States. These survivors are planning the rest of their life and having a family. Families come in all shapes and sizes and cancer survivors become parents in many different ways, including natural conception, use of egg or sperm donors, use of surrogates, and adoption.

Cancer treatments, including radiation and chemotherapy, can impact fertility. Fertility means the ability of a woman to become pregnant naturally or a man to father a child naturally. 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. The Reproductive Medicine Center of Froedtert and the Medical College of WI can help you to decide what is best for you. The fertility experts see patients at:

- Menomonee Falls
  North Hills Health Center
  W129 N7055 Northfield Drive
  Building B, Second Floor, Suite 500
  Menomonee Falls, WI 53051
  1-800-DOCTORS

To learn more about us, please visit froedtert.com/fertility or call us to schedule an appointment. We'll be happy to discuss your fertility treatment options with you.

Further Resources:
- MyOncoFertility.org
  Interactive patient education resource where people can find answers to cancer-related fertility questions.
- Livestrong.org
  Helps you to talk about fertility with your doctor and loved ones and provides financial assistance for fertility preservation.
- AllianceforFertilityPreservation.org
  Provides education and resources around fertility preservation, including a list of financial assistance programs.

How To Be Your Best Advocate

- Ask questions about the impact of treatment on fertility & 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 and acute and long-term effects.
- Utilize psychosocial and/or community support (e.g. Psychology, Social Work, Child Life, Financial Counseling, and Palliative Care).
- You should feel respected and taken seriously without judgment of cultural, spiritual, social, and personal values beliefs and preferences.
- Discuss and ask questions about advance care planning (e.g. Living Will, Advance Directive, Power of Attorney).
- Make sure you understand your diagnosis, prognosis, treatment plan, and recovery. Was this explained to you clearly?
- 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.
- Socialize with other AYA patients.

You should feel respected and taken seriously without judgment of cultural, spiritual, social, and personal values beliefs and preferences.

The Reproductive Medicine Center of Froedtert and the Medical College of WI can help you to decide what is best for you.
It is important to realize that you are not alone in coping with your feelings and fears during treatment.

Being an AYA means you have to treat your cancer differently. There can be a lot of strange things about being in the middle space between being a kid and being an older adult.

Our resources are built to support you through the journey from diagnosis to survivorship.

This section is about encouraging you to talk about your treatment, feelings, and needs with your health care providers and support network.

The Young Adult Oncology Group
414-955-4148 (Ages 18-39)
The Young Adult Oncology Group provides social network opportunities for adolescents and young adults to share experiences and participate in social and recreational gatherings. Follow us on Facebook, search “YAOG Midwest Wisconsin”.

Cancer Caregivers Support Group
For more information call 414-805-3666 or 800-272-3666.
A monthly support group, open to anyone caring for a loved one diagnosed with any type of cancer. This group focuses on the importance of the caregiver’s emotional health. There is opportunity for discussion and sharing of experiences, communication of feelings, relaxation, and stress relief.

National Cancer Institute
cancer.gov/types/aya
Provides accurate information and research about cancer, cancer treatment, and supportive resources for adolescents and young adults with cancer.

Imerman Angels
312-274-5529 imermanangels.org
Connects those fighting cancer with a survivor of the same cancer. Also supports caregiver needs.

Teen Activities
414-955-4148 (Ages 12-17)
FREE social activities outside of the hospital for teens to connect with other teen cancer survivors.

Together We Are Strong: a cancer blog
Subscribe at froedtert.com/together
What does the word “cancer” mean to you? Your cancer experience is different from mine, but we can learn and take comfort from one another. Visit our cancer blog, Together, We Are Strong, where a community of patients, family members, friends, physicians and researchers have started a conversation about cancer.
Empowering

Lookgoodfeelbetter.org
Learn beauty techniques for women with cancer undergoing chemotherapy, radiation, or other forms of cancer treatment. Help combat the appearance-related side effects of cancer treatment. Contact a member of your care team for details.

Small Stones Wellness Center
This wellness center provides wig, skin care and make-up consultation as well as a number of health and wellness classes, programming and mind-body treatments for cancer patients/survivors:
• Yoga
• Tai Chi
• Massage
• Aromatherapy
• Meditation
• Reiki
Offered at locations in New Berlin, Wauwatosa, West Bend, Oak Creek, and Menomonee Falls. Details about wellness programming can be found at froedert.com by selecting Health Resources, Classes, and Events or by calling 414-805-0998.

Holistic Health and Wellness Services, Programs, and Resources
We offer different programs and services to help empower you on your journey through healthy eating and ways to help you feel better about the changes your body is going through.

Nutrition Services
A registered dietitian is a food and nutrition expert who provides assessment and consultation around healthy eating and nutritional needs during cancer treatment. Your doctor may want you to see a dietitian as part of your cancer treatment 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.

Empower
8-week class which provides education on nutrition, exercise, emotional and social issues for cancer survivors. Offered at Wisconsin Athletic Club. Call 414-805-0998 for specific times and dates.

Livestrong© at the YMCA
A researched-based program designed to help adult cancer survivors reclaim their health and begin their journey toward recovery. gwcymca.org/LIVESTRONG-at-the-YMCA

Regular participation in physical activity is very 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.
Join What Was with What Will Be

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 psycho-oncology services at the MACC Fund Center at Children's Hospital of Wisconsin and all Froedtert Hospital locations. Chaplains are available at Froedtert Hospital, Community Memorial Hospital, St. Joseph's Hospital, and Children's Hospital of Wisconsin to provide spiritual 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. They assist families during hospital stays.

Therapy Dog
Trained, certified therapy dogs offer comfort that helps with stress in the hospital. Therapy dogs also help distract from illness and hospital procedures.

Psychon-Oncology
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 can address the mental health needs of patients undergoing cancer care. They help patients to use art during a therapy session.

Social Work
Social Workers meet with patients and families to assess needs. Your Social Worker helps with social, emotional, and financial needs related to the cancer diagnosis and treatment. They also look at work, school, sibling needs, insurance, transportation, and guardianship and custody needs.

Child Life
Child Life Specialists teach healthy coping skills. They prepare patients and families for procedures and help them understand their new diagnosis. They also help the siblings or children of young adult patients.
Expanding the Circle of Support

Advocacy

2bMe lookgoodfeelbetter.org/2bMe
Provides guidance on dealing with skin care, hair loss, and other side effects of cancer treatment for teens.

CaringBridge 651-452-7940 caringbridge.org
Helping friends and family stay connected and organized in support.

GroupLoops.org
Online support community for teens dealing with cancer diagnosis.

LacunaLife.org
Encourages, empowers, and connects young adult cancer survivors and caregivers (18-45) around the world. Provides online wellness support programs and resources, lifestyle encouragement, and peer support community (ex. writing workshop, art workshop, etc.)

MyLifeLine.org
Enables cancer patients to build online support and community.

TheSamFund.org
Support for Young Adult Cancer Survivors.

Sarcoma Foundation of America 301-253-8687 curesarcoma.org
Advocates for sarcoma patients via funding research and awareness.

Stupid Cancer 877-735-4673 stupidcancer.org
Nonprofit that addresses young adult cancer.

TriageCancer.org
Provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources.

The Ulman Cancer Fund for Young Adults ulmanfund.org The Fund has been changing lives by creating a community of support for young adults, and their loved ones, as they fight cancer and embrace survivorship.

Adventure Programs

Angel on My Shoulder 1-800-860-3431 angelonmyshoulder.org
Cost-free relief, support, and camps for patients, caregivers, siblings.

Camp Mak-A-Dream 406-549-5987 campdream.org
Camp in Montana provides medically-supervised, cost-free experience for children, AYA, and families affected by cancer.

First Descents 970-328-1806 firstdescents.org
Camp for young adults, offering kayaking, extreme sports, athletics.

The One Step at a Time Programs 312-924-4220 onesteppcamp.org
Camp experience for children up to 19, also sibling camp, family camp.

Career

Cancerandcareers.org
Cancer and Careers empowers and educates people with cancer to thrive in their workplace, by providing expert advice, interactive tools and educational events.

Job Accommodations Network 1-800-526-7234 askjan.org
Free, expert, and confidential guidance on workplace and employment issues.

Workforce Development- Vocational Rehabilitation https://dwd.wisconsin.gov/dvr/top_ten_list.htm

Scholarships

Cchw.org/medical-care/macc-fund-center/programs-and-services/survivorship-program/scholarships

Stupid Cancer 877-735-4673 stupidcancer.org
Nonprofit that addresses young adult cancer.
Our Mission is to not only help you beat cancer, but to help you live a healthier and stronger tomorrow.

Tips for the journey from those who walked it.

Helpful things to bring to the hospital for treatment or surgery:
- Headphones/ear buds
- Cellphone/mp3 player/tablet
- Chapstick
- Hand lotion
- Peppermint candies for nausea

Look for small victories in every day.

Decorate your room to make it feel like home.

Take advantage of your good days. Get outside whenever you can. Try to continue to do the things you enjoy.

Find ways to express yourself (journaling, knitting, doodling, etc.).

Be prepared to binge watch Netflix. Bring your computer or I-pad with you.

Make relationships with your care team. They will be your biggest advocates.

Reach out to other young cancer survivors.

It’s okay to stay in bed for the day.

Bring someone with you to your appointments.

You might lose some or all of your hair. It’s your choice to wear a wig, hat, scarf, or just be bald. Bald is beautiful too.

Get mad. Get angry. Let it out. Don’t hold it in.

It’s okay to let your emotions show, it doesn’t mean you’re not strong.

Don’t feel that you need to be the “strong one” so that (insert person here) may not worry as much.

Don’t be afraid to ask for help and accept help.

Go to therapy. This is a life changing situation. You may feel things and might need help to process them.

Connect with other AYA Survivors. It’s helpful to find others that are going through or have gone through similar experiences.