

# ESSENTIAL RESOURCES

**FOR ADOLESCENTS AND  
YOUNG ADULTS WITH CANCER**

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# MEET OUR ADOLESCENT AND YOUNG ADULT (AYA) NAVIGATOR




Hello there!

My name is Jennifer Carrera and I am the AYA Clinical Oncology Navigator. We know that having cancer as an adolescent or young adult is very challenging. It may impact school, career, relationships with peers, dating, finances, independence, and starting a family. I am here to help you navigate the complex and unique challenges that come with a cancer diagnosis and make it a little less overwhelming.

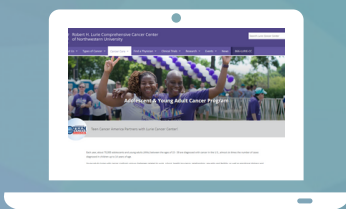
Please don't hesitate to reach out to me if you have any questions. We hope the resources included in this packet will be useful to you.

**Jennifer Bourneuf Carrera, MSW, LCSW**  
*AYA Clinical Oncology Navigator*

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Visit our websites:



[cancer.northwestern.edu/AYAO](http://cancer.northwestern.edu/AYAO)

[luriechildrens.org/ayao](http://luriechildrens.org/ayao)

**JOIN US  
ONLINE**



Follow our AYA program on  
Instagram and Facebook at

**@LURIEAYA**



# recommended reading & tools



\*Click on images or text for links

**NCI** provides cancer related education, research resources, and disease specific information.



**Cancer.net** has trusted, compassionate information for people with cancer & their families.



**The American Cancer Society** provides expert information, patient support, and education related to cancer.



**Livestrong** provides free cancer navigation services as well as education about cancer related topics and support.



## NCCN AYA Guidelines:

A resource for cancer patients to better understand what doctors say and prepare you for treatment.



**Mango Health** smartphone app helps you manage your medications & create healthy habits while collecting points and prizes.



**Abridge** is a smartphone app that allows you to record all the details of your care and stay on top of your health.



**AceCancer** is a web app that helps you monitor medications, symptoms, and key health indicators.



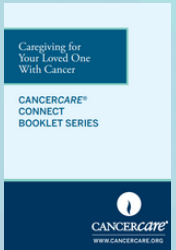
**American Cancer Society's "Sex and the adult Female with Cancer"** provides information about cancer, sex, and sexuality.



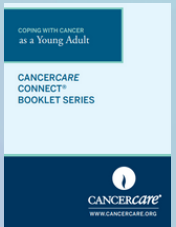
**American Cancer Society's "Sex and the Adult Male with Cancer"** provides information about cancer, sex, and sexuality.



**NCI's "Caregiving for your Loved One With Cancer"** is filled with tips from social workers about how to cope with the emotional and practical challenges of cancer.

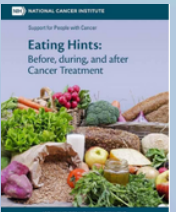


**NCI's "Coping with Cancer as a Young Adult"** offers helpful guidance and support on how to cope with many of the changes, challenges and adjustments related to cancer, along with places to find support.



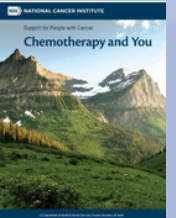
## NCI's "Eating Hints":

Use this booklet before, during, and after cancer treatment. It covers common types of eating problems and ways you can manage them.



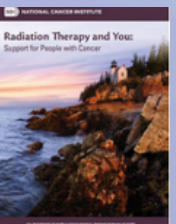
## NCI's "Chemotherapy and You":

This booklet has facts about chemo and its side effects. It highlights ways you can care for yourself before, during, and after treatment.



## NCI's "Radiation Therapy and You":

This booklet has facts about radiation therapy and side effects you may have. It also highlights ways you can manage side effects.





# local support resources



\*Click on images or text for links



## Northwestern Young Adult Cancer Monthly Programming:

We have 2 monthly support groups. The 1st Tuesday of the month at 6:00pm is group open to those who have been diagnosed with cancer between the ages of 15-39 and are currently 18-39. The 2nd Tuesday of the month at 6:00pm is group dedicated to their supporters. Every other month on the 3rd Wednesday at 6:00pm is "It's a C Thing" Hangout. This hangout is open to anyone diagnosed with cancer between the ages of 15-39 as well as a guest. You must have received care at Northwestern or Lurie Children's Hospitals to participate. Contact Jennifer Carrera at [jennifer.carrera@nm.org](mailto:jennifer.carrera@nm.org) for more information.

## Brain Tumor Support Group:

Monthly support group for brain tumor patients, survivors, families, and caregivers. Third Monday of the month at 5:00pm. Contact Chris Balmaceda at [cbalmace@nm.org](mailto:cbalmace@nm.org) for more information.



## PeerWISE and ParentWISE at Lurie Children's Hospital:

Mentoring program for patients and parents to talk with someone who has been in their shoes. Email [parentwise@luriechildrens.org](mailto:parentwise@luriechildrens.org) for more information.



Have a monthly networking group open to AYAs as well as a group for parents of children under 18 who have a loved one with cancer. Also have monthly socials for young adults with cancer, teen camp, teen multimedia contest, and the Red Door Squad for teens. [Click here for more information.](#)



Have a monthly online group for young adults with cancer. Contact [mmengesha@wellnesshouse.org](mailto:mmengesha@wellnesshouse.org) for more information.



Have a monthly support group for young adults with cancer. Contact Katie at [khull@cancerwellness.org](mailto:khull@cancerwellness.org) for more information.



Offer a variety of monthly support groups ranging from scanxiety to caregiver, to young adult brain tumor. [Click here to sign up.](#)



# cancer wellness resources



\*Click on images or text for links



**Mindfulness Meditation Class:** Bi-monthly mindfulness meditation class for patients, survivors, and caregivers ages 15+. In partnership with True North Treks. These events are hosted virtually through True North Treks.

**Healing Boutique:** Wig fittings and vouchers available. Appointments available during infusion in Galter, Prentice, and Arkes Pavillions. Call 312-472-5302 for more information.

**Simply From the Heart:** Provides beauty services free of charge including hair styling, makeup, nail polish, mini facials, and hand massage.

**Osher Center for Integrative Medicine:** Offers integrative and wellness services including chiropractic medicine, massage, acupuncture, nutrition, fitness and wellness classes, energy medicine, and more.

Wellness programs including yoga, meditation, art, tai chi, jewelry, cooking classes, etc. Gilda's Club also offers regular programming on Galter 21.



Regular wellness programs including yoga, tai chi, Pilates, networking, meditation, cooking, nutrition and more. Locations in Hinsdale and throughout the Chicago metro area.

Regular wellness classes including yoga, exercise for cancer, tai chi, knitting, mindfulness, walking, etc. Locations in Northbrook and Grayslake, Illinois.



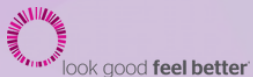
Programs include education, support, nutrition, massage, relaxation, fitness, yoga, art, and more. Located in Geneva, Illinois and also have programming on Galter 21.

Programs include counseling, fitness, nutrition/diet, body image, family & children, yoga, cooking, zumba, knitting, & more. Located in Mokena, IL.



Offerings include massage, yoga, chi gong, art therapy, cooking, reiki, tai chi, yoga, support groups, meditation. Located in Munster, IN.

Virtual online workshops from Look Good Feel Better to learn about skin care, makeup, wigs, and head coverings for female cancer patients.



Information on medical cannabis from the Illinois Department of Public Health.

Provides free online art, music, and writing sessions for patients, caregivers, & medical professionals.



Information on complementary, alternative, & integrative health, information on how to find practitioners, and more.

In partnership with the Leukemia and Lymphoma Society, you receive a free one-on-one phone consultation with dietitians with expertise in oncology.



About Herbs app provides comprehensive information about herbs, botanicals, supplements, complementary therapies and more.



# social & support resources



\*Click on images or text for links



Online support programs for young adult cancer patients, survivors, and caregivers.



Connects those at any point in their cancer journey with mentors to be able to ask questions and get support.



Offer a magazine curated for AYA cancer patients/survivors, a podcast, regular digital meetups, a Facebook group and more.



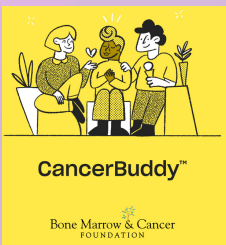
First Connection Program is a program for blood cancer patients to get support from someone who has been through it.



Host regular digital meetups, webinars, an annual conference, CancerCon, local meetups, and more for young adults with cancer.



Provides free, support services for young adults affected by cancer as well as information and resources. They host regular online support groups for AYAs.



A social support network for people facing cancer. Get matched with other patients, survivors, or caregivers. Download for free in the App Store.



With a scarcity of resources geared specifically to men's unique needs, Cancer Dudes provides education and resources in order for men to successfully move past their cancer experience.



Offers the Play it Back Music Program, online hangouts, an AYA newsletter, and more. Contact Kara at [kara@teencanceramerica.org](mailto:kara@teencanceramerica.org).



Offers free support to women diagnosed with cancer while pregnant. Connect women who are pregnant with cancer to others who have been there.



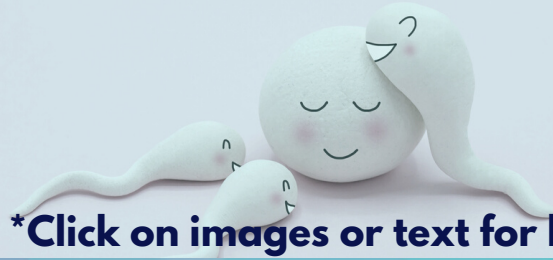
Mobile app social community for people affected by cancer to connect to others with similar experiences.



Helps cancer patients/survivors connect and share experiences about cancer with others who understand.



# fertility preservation



**\*Click on images or text for links**



**PATIENT NAVIGATOR**

Connect with the Northwestern fertility navigator in this online patient navigation website that educates patients about their options, & watch personal stories. Call 312-503-3378 for more information.



Helps you understand your fertility risks and options and get access to fertility preservation discounts. You can also call to speak with a fertility navigator.



An international, interdisciplinary initiative designed to explore the reproductive future of cancer survivors.



Educates people whose fertility may be threatened by their disease or it's treatment. This website is very helpful in understanding your options.

**SAVE MY FERTILITY**

A resource for cancer patients to learn more about preserving their fertility before and during cancer treatment.



Helps patients find fertility preservation services in their area as well as educates patients on their options.

**\*Click on images or text for links**



# camps, retreats, & adventures



Aims to empower AYAs affected by cancer to reclaim the lives and futures that cancer took from them.



Outdoor adventures for AYAs, creating the space to play, connect, and have fun outdoors (ages 21-40).



A free outdoor adventure experience designed to empower them to climb, paddle, and surf for AYA survivors.



Provides camping program in Arizona for young adults dealing with life threatening illness.



Free week-long outdoor camps, meetups, and online support programs for those who have been diagnosed with cancer.



Provides cost-free Montana experiences for individuals and families affected by cancer.



Enriches lives through community and the outdoors as a way to move forward after cancer (ages 18-39).



Outdoor adventure camp for children and teens with cancer in New York (ages 6-20).



The Cassie Hines SHOES CANCER FOUNDATION

Guides AYAs to peer support programs, including cancer camps, & encourages participation in programs (ages 18-39).





# financial assistance, scholarships, & employment

\*Click on images or text for links



Provides financial assistance grants for 21-39 year olds post treatment or on maintenance therapy.



Provides gifts to fund creative passions as well as integrative therapies such as acupuncture or therapeutic massage. (Ages 18-39)



Direct financial assistance for AYAs with cancer. (Ages 15-39)



Provides financial assistance for co-payments of cancer treatments for those insured.



Co-pay assistance and patient aid programs for specific diseases.



Provides financial assistance for specific diseases through grants to help with co-pays, premiums, deductibles, and out-of-pocket expenses.



Provides scholarships for cancer patients and survivors to continue their education.



Financial and co-pay assistance programs for cancer-related costs.



Provides college scholarships for young adults with cancer. (Ages 17-39)



Guidance on workplace accommodations & disability employment issues.



Provides need-based financial support to young adults who are pursuing higher education in treatment and beyond. (Ages 18-35)



Provides information on the practical and legal issues that may impact individuals diagnosed with cancer.



Financially assists cancer patients by awarding scholarships for education.



Offers \$1000 college scholarships for students who have had cancer.



Support for people with cancer who are trying to manage their cancer & career.



Provides college scholarships for young adults with cancer.

Provides information and education about cancer-related legal issues to the public through its toll-free national phone line and webinars.



Comprehensive listing of college scholarships for cancer patients and survivors.





# insurance resources

**\*Click on images or text for links**



## Cancer Insurance Checklist

A checklist designed to help you compare health insurance plans and consider your health needs when shopping for insurance.



A toolkit designed to help you navigate finances during and after cancer. Includes sections on health insurance, disability insurance, financial assistance and more.



Social Security pays disability benefits to people who cannot work because they have a medical condition. Apply for benefits by calling 1-800-772-1213 or also apply online.



Website for open enrollment. Multiple private insurance plans to choose from, no exclusions for pre-existing conditions, no lifetime limits, possible subsidy to help pay premiums.



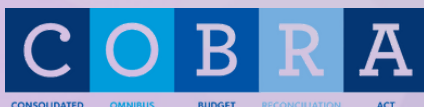
## Medicaid

Medicaid is joint federal/state insurance for low income and disabled individuals. Find information about Medicaid and learn how to apply.



## Medicare

Medicare disability: Medicare eligibility expanded to include certain disabled individuals under the age of 65. Non-elderly individuals who have received disability payments for 24 months are eligible. Find information about Medicare and learn how to apply.



COBRA stands for the Consolidated Omnibus Budget Reconciliation Act and it gives workers and families who lose their health benefits the right to choose to continue health benefits for limited periods of time under certain circumstances.

# do you support an AYA?



\*Click on images or text for links



Mobile app that helps to coordinate friends and family to practically support, communicate updates, and ensure that you are not alone.



Bring friends and family together for support. You can create a registry, send gifts, update journals and more.



Offers a gift registry for cancer patients, a journal to keep people updated, and a care calendar.



Using their b-there connection tool, you can stay connected to your support network and share information.



A personal health journal website to rally friends and family.



Cancer specific networking site to connect through private community website, blog, assign care coordinators and more.



Support for spousal caregivers, resources, literature, & other resources for caregivers.



A care calendar website and the easiest way to organize meals and other help for friends and family in need.



Provides quality information, support & resources for family caregivers. Services include care planning, direct care skills, wellness programs, respite services etc.

\*Click on images or text for links



## survivorship resources



Website for pediatric cancer survivors to increase awareness and knowledge about life-long healthcare needs.



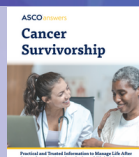
Survivor led cancer advocacy organization to empower survivors through programs which provide tools for self-advocacy.



Provides tools and resources to empower cancer survivors to live healthier lives.



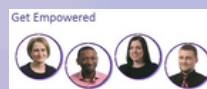
LLS has great resources on follow up care and survivorship.



This booklet is designed to help you figure out what is next; to help you and your family prepare for life after treatment.



This booklet covers your new normal after treatment, ways to manage physical changes, coping with your feelings, going back to work and more.



A video education series for survivors of childhood cancers.

### Survivors Taking Action and Responsibility (STAR) Program:

Risk-based clinical care using survivorship guidelines for childhood cancer survivors at the Robert H. Lurie Comprehensive Cancer Center and at Lurie Children's Hospital.



# helping children when a family member has cancer

\*Click on images or text for links



## Telling Kids About CANCER

Telling children about a cancer diagnosis can be overwhelming for any parent. This tool will support you every step of the way.



Dedicated to comforting, encouraging, and empowering siblings during their family's battle against cancer.

## MARJORIE E. KORFF PACT PROGRAM PACT Parenting At a Challenging Time

Provides parent guidance consultations to parents with cancer and their partners.



NCI's, "When your Brother or Sister Has Cancer" is a guide for teens with a brother or sister who has cancer. You will hear from teens who are like you, and get ideas of what can help when things feel hard.

## riprap when a parent has cancer

Riprap.org is a site for teenagers who have a parent with cancer where they can learn more about cancer and its treatment through real stories and other support.



Cancer Care's "Helping Children When a Family Member has Cancer" will help you start the conversation about cancer and give you the tools to keep it going.



Support programs and resources for kids and teens with a parent with cancer.



Creates thriving communities of kids supporting kids during and beyond their parents' cancer journeys.

\*Click on images or text for links



## lgbtq resources

### Escape

An escape for LGBTQIA+ adolescents and young adults experiencing cancer. Provides support groups, zoom events to connect with others, information and more.



Online resources for the LGBTQ2+ community including a searchable information database, a connection portal, and stories from others.



Provides cancer related programs, services, and support for LGBT people and other sexuality and gender diverse people and communities.



Works to improve the lives of LGBT cancer patients and survivors through education, training, and advocacy.



# wish granting

\*Click on images or text for links



**Nikolas Ritschel Foundation**  
Take one step...

Wish granting program for young adults with a cancer diagnosis. (Ages 18-24)



dreamfoundation

Saving terminally-ill adults and their families by providing end-of-life dreams that offer inspiration, closure and comfort.



Provides a little wish for childhood cancer patients that brings hope, comfort and joy.



Enriching the lives of children and young adults by granting sports and celebrity athlete wishes.



Life List is their wish granting program for adolescent and young adult cancer patients.



Grants weddings and vow renewals to couples facing serious illness or life-altering circumstances.

Provides life grants to young adults with a life threatening illness to fulfill a dream or project that will make a difference in your life and the lives of others. (Ages 18-30)



Wish granting for children and young adults (ages 0-20) who have been diagnosed with a life threatening condition.



# clinical trial resources

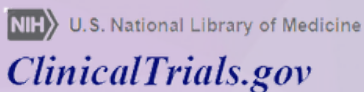
\*Click on images or text for links



Searchable database of clinical trials offered at the Robert H. Lurie Comprehensive Cancer Center. Call 312-695-1102 to speak to the clinical trial navigator.



Searchable database of clinical trials offered at Lurie Children's Hospital.



List of all available clinical trials nationwide, both cancer related and not.



Helps to cover the cost of participating in FDA clinical trials for patients with no other treatment options.



Clinical trial navigation service to link patients to available clinical trials around the nation.