

# ESSENTIAL RESOURCES

## FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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# MEET OUR ADOLESCENT AND YOUNG ADULT (AYA) TEAM


Hello there!

We know that having cancer as a teen or young adult is very challenging. It may impact school, career, relationships with peers, dating, finances, independence, and starting a family. We are 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 us if you have any questions. We hope the resources included in this packet will be useful to you.



**Jennifer Bourneuf Carrera, MSW, LCSW**  
*AYA Counselor*

 **312-503-3779**

 **[jennifer.carrera@nm.org](mailto:jennifer.carrera@nm.org)**

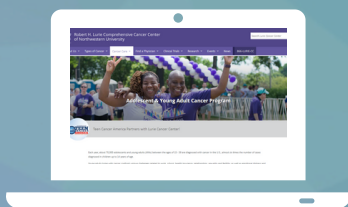


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Visit our websites:



**[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.



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

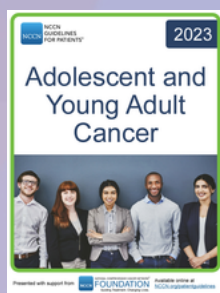


**Livestrong** provides free cancer navigation services as well as education about cancer related topics and support.



## **NCCN AYA Guidelines:**

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

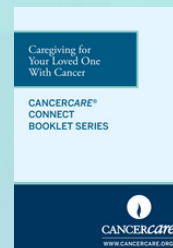


**Abridge** is a smartphone app that allows you to record all the details of your care and stay on top of your health.



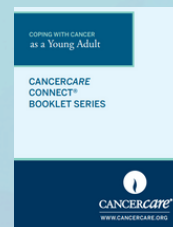
## **NCI's "Caregiving for your Loved One With Cancer"**

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.



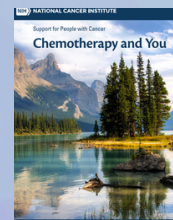
## **NCI's "Eating Hints":**

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



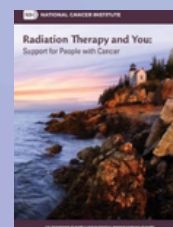
## **NCI's "Chemotherapy and You":**

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 groups



\*Click on images or text for links



## Northwestern Young Adult Cancer Monthly Programming:

We have 2 monthly support groups that run September-May each year. The 1st Tuesday of the month at 6:00pm is a group open to those who have been diagnosed with cancer between the ages of 15-39 and are currently 18-39. You must have received care at Northwestern or Lurie Children's Hospital to participate. The 2nd Tuesday of the month at 6:00pm is a group dedicated to their supporters. We also have periodic "It's a C Thing" hangouts. These hangouts are open to anyone diagnosed with cancer between the ages of 15-39 as well as a guest. Contact Jennifer Carrera at [jennifer.carrera@nm.org](mailto:jennifer.carrera@nm.org) for more information.

**Click here to see other support groups at the Lurie Cancer Center.**



## 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.



**GILDA'S CLUB CHICAGO**  
An Affiliate of the  
CANCER SUPPORT COMMUNITY

Have a monthly support group open to AYAs (18-39) who have been impacted by cancer. Also have socials for young adults with cancer, teen camp, teen multimedia contest, and the Red Door Squad for teens. [Click here for more information.](#)

They also offer Spanish language, LGBTQ and Black Women of Ethnicities support groups. Contact [info@gildasclubchicago.org](mailto:info@gildasclubchicago.org) for more info.



Have a monthly support group for young adults with cancer and a young women's group. Contact Alana at [alebovitz@cancerwellness.org](mailto:alebovitz@cancerwellness.org) for more information. Contact [nbarquin@cancerwellness.org](mailto:nbarquin@cancerwellness.org) for Spanish speakers.



## Living Well Cancer Resources

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



Have a monthly group called "Young Adults with Cancer Connections". Contact [nbennett@wellnesshouse.org](mailto:nbennett@wellnesshouse.org) for more information. Also have an in person Spanish speaking support group. Contact [igarciaperez@wellnesshouse.org](mailto:igarciaperez@wellnesshouse.org) for more information.



# cancer wellness resources



\*Click on images or text for links



**Northwestern Medicine**  
Osher Center for Integrative Medicine

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



Living Well Cancer Resources offers programs include education, support, nutrition, massage, relaxation, fitness, yoga, art, and more. Located in Geneva and Warrenville, Illinois.



Wellness programs including yoga, meditation, art, tai chi, jewelry, cooking classes, etc. They also offer in-person programming at the cancer center downtown.



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.



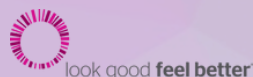
Offerings include massage, yoga, chi gong, art therapy, cooking, reiki, tai chi, yoga, support groups, meditation. Located in Munster, IN.



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



Advocates for Community Wellness aims to reduce barriers to health equity by offering holistic services for mind, body and spirit.



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.



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



The Leukemia and Lymphoma Society offers 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.



Provides wellness & exercise services in Bronzeville to promote healthy living and to reduce the risk of cancer.



Provides beauty services free of charge including hair styling, makeup, nail polish, mini facials, and hand massage.





# social & support resources



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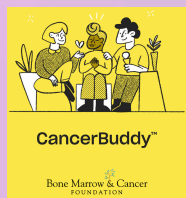
Online support programs for young adult cancer patients, survivors, and caregivers.



Offer a magazine curated for AYAs, a podcast, regular digital meetups, Perkatory, a Facebook group and more.



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



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



Offer the Play it Back Music Program for AYAs to dive into songwriting and producing as a form of self-expression.



Offer regular virtual programs for young adults with cancer including socials, support groups and more.



Provide services in Chicagoland including patient navigation, education, support groups, transportation and food assistance.



Mobile app social community for people affected by cancer to connect to others. They also have a group for those 40+.



A resource hub and community for young adults and women of color to access support, advice, and medical insight.



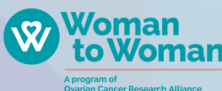
Connects those at any point in their cancer journey with mentors to be able to ask questions and get support.



Connecting Champions asks AYAs with cancer what they are passionate about and teams you up with a mentor to help achieve a brighter future.



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



A mentor support program at Northwestern Medicine that pairs gynecologic cancer patients with trained survivor mentors for emotional support.



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



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



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



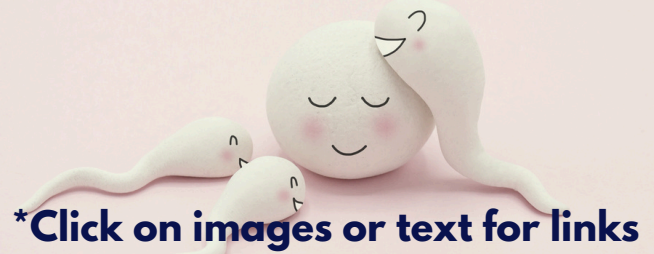
Helps cancer patients/survivors connect and share experiences about cancer with others who understand.



A national women's health and oncology organization providing education, awareness, advocacy and hands-on support to young women (15-50) before, during and after breast cancer.



# **reproductive & sexual health**



**PATIENT NAVIGATOR**  
for fertility preservation

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.

## **Center for Sexual Medicine and Menopause**

Provides specialized care for women of all ages for menopause, sexual medicine and vulvar and vaginal health.

## **Northwestern Medicine Urology**

Provides specialized care for men in the areas of fertility, sexual dysfunction, sexual health, gay and bisexual urology and more.



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.



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. Discover which states have laws requiring coverage for fertility preservation and how you can get involved.

## **Financial Resources for Fertility Preservation**



chick mission



Worth the Wait



Inova offers a variety of virtual support groups and programs with several with a focus on sexual health.



Cactus Cancer has a program called Awkward Auntie where you can write in questions about relationships or sex that you can't ask anyone else.



**American Cancer Society's "How Cancer Can Affect Sex and Intimacy"** provides information about cancer, sex, and intimacy.

**American Cancer Society's "Managing Sexual Side Effects as a Woman with Cancer"** provides information about cancer and sex specific to women.

**American Cancer Society's "How Cancer Can Affect Sexual Desire for Men"** provides information about cancer and sex specific to men.



# camps, retreats, & adventures



Aims to support young adults and caregivers affected by cancer to “find direction through connection” through free backpacking and canoeing treks. (Ages 15+)



A free outdoor adventure experience designed to empower young adults impacted by cancer to climb, paddle, and surf. (Ages 18-45)



Free week-long outdoor camps, meetups, and online support programs for those who have been diagnosed with cancer. (Ages 18+)



A free, outdoor, adventure, wellness and community program that helps young adult cancer survivors find healing and renewal beyond cancer. (Ages 19-39)



Offers peer support and Base2Summit, an adventure-based program focusing on wellness, adventure and connection. (Ages 18-40)



Way Up is a 7 day adventure in Italy for those who have been diagnosed with cancer. This program allows you to (re)discover physical abilities and autonomy while connecting with peers. (Ages 18-45)



Offers camp experiences and other educational and excursion programs throughout the year that allow children with cancer to just be kids. Patient, sibling and family camps and patient-only trips. (Ages 5-19)



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



Provides camping program in Arizona for young adults dealing with life threatening illness. (Ages 18-24)



Provides cost-free Montana experiences for individuals and families affected by cancer. (Ages 13-35)



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



The We are Ocean Cancer Program provides ocean-based adventures for teens and young adults impacted by cancer in Southern California. (Ages 15-39)



Breathe Now retreats for young adult cancer survivors. The 4 day retreat harnesses the transformational powers of yoga, meditation and psychosocial breakout sessions. (Ages 18-39)



Young Adult Cancer Camp offers a relaxing getaway to unwind, connect with old friends, and meet new friends who know what it's like to face cancer. (Ages 18-39)





# financial assistance, scholarships, & employment

\*Click on images or text for links



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



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



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



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



Offers financial assistance and support to children and young adults with life-threatening illnesses.



Offers an annual survivors grant to young adults with cancer and financial need.



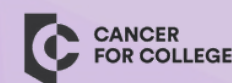
Provides college scholarships for young adults with cancer. (Ages 17-39)



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



Financially assists cancer patients by awarding scholarships for education.



Provides college scholarships for young adults with cancer.



Comprehensive listing of college scholarships for cancer patients and survivors.



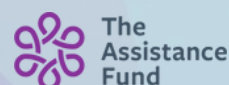
Provides financial assistance for co-payments of cancer treatments for those insured.



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



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



Helps patients facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses.



Offer financial assistance and co-pay assistance programs for rare diseases.



Financial assistance for out-of-pocket medication costs, insurance premiums, and even transportation expenses.



Guidance on workplace accommodations & disability employment issues.



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



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



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





# 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.



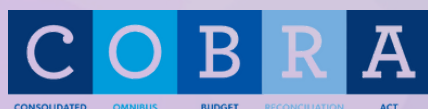
## Medicaid

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.



A personal health journal website to rally friends and family.



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



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



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



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



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



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



Provides support, travel support, childcare support, and a sense of community for caregivers.

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## survivorship resources



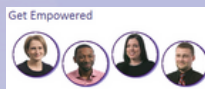
Website for pediatric cancer survivors to increase awareness and knowledge about life-long healthcare needs.



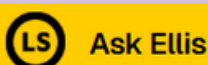
Survivor led cancer advocacy organization to empower survivors through programs which provide tools for self-advocacy.



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.



A cancer survivorship app developed by Livestrong, designed to answer questions and share resources and support. Download in the app store.

### 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 Lurie Children's Hospital.



American Cancer Society has great resources and information on living well after cancer treatment.

### Northwestern Medicine Adult Survivorship Clinics:

Comprehensive and disease-specific services for Northwestern patients who have completed initial treatments (breast, leukemia, lymphoma & testicular cancers).



LLS has great resources on follow up care and survivorship.





# helping children when a family member has cancer

\*Click on images or text for links



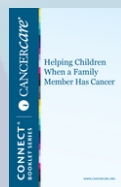
This guide from the Cancer Support Community called "What Do I Tell the Kids" offers great information and resources for parents.



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.



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



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.



Provides young cancer survivors who are parents of small children with support through grants, groups, and other resources.



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



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



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

\*Click on images or text for links



## lgbtq resources



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.



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



Empowers LGBTQ+ individuals through comprehensive resources, education and support. From the OutList directory of affirming healthcare providers to mentorship, peer support, consulting services and more.



Gilda's Club offers a monthly group for those who identify as part of the LGBTQIA+ community and have been impacted by cancer.





# 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)

Provides a little wish for childhood and young adult cancer patients that brings hope, comfort and joy. (Must be receiving care in pediatric setting)

Life List is their wish granting program for adolescent and young adult cancer patients. (Ages 18-39)

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. (Ages 18-30)

Offers a wish granting program for adults battling a terminal illness. (Ages 21-65)

Offers a wish granting live music experience for anyone with a life-threatening medical condition. (All ages)

Enriching the lives of children and young adults by granting sports and celebrity athlete wishes. (Ages 5-25)



dreamfoundation

Saving terminally-ill adults and their families by providing end-of-life dreams that offer inspiration, closure & comfort. (Ages 18+)



Grants weddings and vow renewals to couples facing serious illness or life-altering circumstances. (Ages 18+)



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



marsha leigh foundation

Provides families in need facing a terminal cancer diagnosis with an unforgettable experience when it matters most.



Jack & Jill  
Late Stage Cancer  
FOUNDATION

Offers WOW! Experiences for children who face the loss of a parent to cancer.



Take The Trip  
Foundation

Sends young families impacted by terminal illnesses on one special adventure together.



## 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 for personalized assistance.



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



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



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



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