Psychosocial Services Resource Guide for Adolescent and Young Adult Survivors of Cancer

Children's Hospital of Philadelphia®
Cancer Center
www.chop.edu/cancer

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This Resource Guide was created to summarize important resources that may be helpful to adolescent and young adult (AYA) survivors of cancer. We at Children's Hospital of Philadelphia hope that as you are planning for the future or facing a particular concern that you can use this guide to quickly access helpful information. The services listed in this guide all exist to support survivors with financial, employment, emotional, social, and health needs or concerns.

We have focused on including many resources available in the tri-state (PA, NJ, DE) area. Given the huge number of resources nationwide, there are more services available to you than are listed in this guide.

Please note: The availability of some of the resources/groups mentioned in the handbook may change over time, so please check directly with the organizations for the most updated information.

If you have questions about any of the resources in this guide, please connect with a member of our Cancer Center Psychosocial Team.

Our Psychosocial Team is comprised of psychologists, social workers, child life specialists, creative arts therapists, chaplains and teachers who support cancer patients, families and medical staff.

If you aren't currently connected to a member of the psychosocial team, please reach out to our Patient Resource Navigator by email at **onconavigator@chop.edu**.

Read more about our Psychosocial Team and their services at **https://www.chop.edu/centers-programs/oncology-psychosocial-services-program**

TRANSITION TO ADULTHOOD: SCHOOL, EMPLOYMENT, AND DAILY LIFE RESOURCES AND ACCOMMODATIONS

School Supports for Oncology Patients

For most adolescents and young adults, school is a big part of daily life and school achievement is necessary to attain career and independent living goals. After cancer diagnosis and treatment, you may find that you need more support than you did before. This may be because you have missed a lot of school, because your illness affects how you learn, or both.

The CHOP Cancer Center has people and resources to help you figure out what you need to succeed. We've also put together materials to help you ask for what you need.

School Accommodations and Modifications

Your illness and treatment may have caused you to need accommodations and/or modifications to your school program.

Accommodations are changes to school materials or to the learning environment that help you to access the same curriculum as everyone else. For example, you may need large print, access to a school elevator, or to sit near the teacher in class. Accommodations vary widely and are based on your specific needs.

Modifications are changes to how you're taught and how the school program is designed. For example, you may need different classes or teaching techniques to help you learn. Modifications also vary widely and can be used for all or part of your school day.

Taken together, the system of giving students these kinds of supports is known as special education. People sometimes think that **special education** always means a special school or special class. This is not the case.

There are federal laws that ensure students with disabilities get what they need both in high school and in postsecondary settings, such as community college or university. We will provide some extra resources for you to learn more about your legal protections, but also want to explain briefly how these laws work to protect you.

504 Plans

If you need **accommodations** only, you will need a 504 plan. 504 plans are for students who have **mental or physical impairments** that impact a variety of areas of life, including **walking, breathing, learning, sleeping** and many more. These impairments are part of the legal definition of a **disability**. This plan is named after Section 504 of the Rehabilitation Act of 1973. This is a civil rights law that protects any person with an impairment who tries to access federally supported facilities, including public schools.

Most students who have cancer are entitled to 504 plans, and they often continue to need them after treatment. To get a Section 504 plan, you or your caregivers can present **medical documentation** of the reason or reasons you need a plan.

Most 504 plans are simple, written documents created by the school counselor or nurse that are shared with all school staff. It's a good idea to know exactly what is in your 504 plan, and to keep a copy for your records.

Many of the accommodations in your 504 plan can be implemented in the college classroom.

Individualized Education Plans (IEPs)

If you need both **accommodations and modifications,** you may need an IEP. These plans identify areas in which you need assistance and set **annual goals** for growth in reading, math and other areas as needed. Students who qualify for IEPs meet criteria for one or more of thirteen disability categories defined by the Individuals with Disabilities Education Act, a federal law protecting students between the ages of birth to 21 who attend public schools.

IEPs are not only for core subjects. You can also get access to **related services** through your IEP, such as speech therapy, physical therapy, vision therapy, counseling services or nursing services.

Your IEP should be updated at least annually, and as a teen or young adult, you are a key part of your IEP team. You should understand the parts that make up your plan, and the people who are responsible for making sure your plan is implemented or followed through on.

Finally, your IEP team is responsible for planning your **transition** to adult life. This means supporting you in your goals to learn job skills, to develop independent living skills, and to apply to trade school or college.

How Students Get IEPs
Students get IEPs in two main ways. Your school team can refer you for evaluation if they worry that you're struggling to keep up with the curriculum. Often, families notice that their child is having more difficulty with school and will request an **evaluation** by a school psychologist and other school staff, such as physical therapists and occupational therapists.

CHOP Resources

At CHOP, there are professionals who understand that your schooling may have been greatly affected by your cancer and treatment. We are invested in your education and welcome the opportunity to help you access what you need in school.

CHOP Oncology Psychosocial Services Program

https://www.chop.edu/centers-programs/oncology-psychosocial-services-program

The Oncology Psychosocial Services Program is staffed by an expert team of psychologists, social workers, child life specialists, creative arts therapists, chaplains and teachers who support cancer patients, families and medical staff at Children's Hospital of Philadelphia's Cancer Center. If you have a relationship with someone on the psychosocial team, talk to them about your school concerns.

Neuropsychological Testing
If you're concerned that you're struggling with learning, especially if the way you think and learn seems to be changing over time, you can ask your CHOP providers about neuropsychological testing. Some youth who have been treated for cancer have **neurocognitive late effects** of their treatment. This means that treatment may have changed your attention, memory, language, executive functioning, visual-spatial functioning and fine motor skills. Neuropsychological testing can identify specific neuropsychological challenges and make recommendations for education remediation, school and home accommodations, and appropriate support services.

You can read more about this here: *https://www.chop.edu/services/oncology-neuropsychology-screening-program*

Education Coordination
If you need more support in school, CHOP's Hospital School Program has certified teachers who work with neuropsychologists, social workers and your medical team. They will talk with your school team about what you need. Education Coordinators can participate in 504 plan and IEP meetings and help you understand your plan and advocate for changes to your plan. Education Coordinators can talk to you about your transition plan and they can provide information about scholarships and other opportunities for CHOP oncology patients.

Education Coordinators work in the Hospital School Program. Read more about the program here: *https://www.chop.edu/services/hospital-school-program*

Additional Educational Resources

Below are some additional resources that provide services and/or educational materials for individuals with learning disabilities and other disabilities.

Education Law Center — New Jersey
https://edlawcenter.org/
60 Park Place, Suite 300
Newark, NJ 07102
elc@edlawcenter.org
Provides legal guidance and support to New Jersey residents with disabilities and their families.

Education Law Center — Pennsylvania
www.elc-pa.org
1800 JFK Blvd., Suite 1900-A
Philadelphia, PA 19103
215-238-6970
Provides free legal assistance to parents, students and advocates on education law matters, and advises parents of their rights to special services under the law.

National Center for Learning Disabilities

www.ncld.org

info@ncld.org

Provides resources related to learning disabilities, referral services, educational programs, and assistive technology, or any device that provides support to those with disabilities, like a wheelchair or even internet access. The website has a searchable database that helps locate nearby education resources through ZIP code.

New Jersey Department of Children and Families, Adolescent Resources

https://www.nj.gov/dcf/adolescent/

dcf_adolescentservices@dcf.state.nj.us

609-888-7100
This website lists different resources funded by the NJ Department of Children and Families that are meant to support adolescents and young adults with various services including housing, life skills, mentoring, employment/training, educational support, youth advocacy and healthcare.

New Jersey Department of Education, Office of Special Education Parental Rights and Engagement

https://www.nj.gov/education/specialed/parents/

The Parental Rights and Engagement webpage offers information about Parental Rights in Special Education (PRISE), school-based family resources, community-based family resources, special education parent advisory groups information, and the New Jersey Department of Education quick links. There is also information about the New Jersey Department of Education Special Education Ombudsman. It also provides additional resources for facilitated individualized education programs (FIEP), Individualized Education Program (IEP) development and resources, dispute resolution, and e-learning opportunities for dispute resolution.

New Jersey Department of Education, Special Education Ombudsman

https://www.nj.gov/education/specialed/parents/

OSEinfo@doe.nj.gov
609-376-9060
This resource describes the role of the Special Education Ombudsman, which is to serve as a resource to provide information and support to parents, students and educators regarding special education rights and services. In addition to serving as a source of information for parents, students and educators to help them better understand state and federal laws and regulations governing special education, the ombudsman also provides information and support to parents of students with disabilities to help them understand and navigate the process for obtaining special education evaluations and services.

New Jersey Educational Opportunity Fund

https://www.nj.gov/highereducation/EOF/EOF_Eligibility.shtml

609-292-4310
This resource provides financial assistance and support services, including counseling, tutoring and developmental course work, to students from educationally and economically disadvantaged backgrounds who attend participating institutions of higher education in the State of New Jersey.

New Jersey Pathways to Academic and Career Exploration to Success (PACES)

https://www.nj.gov/njyrs/education/paces/

The PACES program supports current or former foster youth and young adults in their successful transition to and retention in post-secondary education (including career technical education) and workforce readiness. The program is administered by community agencies that oversee services for particular regions. The site includes a list of PACES provider agencies with the counties served.

New Jersey Transition Toolkit

https://www.nj.gov/education/specialed/programs/njtransition/

This resource is designed to assist school staff and students with disabilities and their families in their efforts to prepare students with disabilities for entry into a successful adult life after high school.

New Jersey Youth Resource Spot

https://www.nj.gov/njyrs/

This is a hub that includes information and resources for the AYA population including education.

Parent to Parent of Pennsylvania

www.parenttoparent.org

888-727-2706
This resource is a peer support program for parents or caregivers of children or adults with disabilities or special needs. The organization can work to match you to a family that has experienced similar situations or challenges you are seeking support for.

The PEAL Center

https://pealcenter.org/

866-950-1040 toll free
412-281-4404
215-567-6143
PEAL works with Pennsylvania families, youth and young adults with disabilities and special healthcare needs to help them understand their rights and advocate for themselves.

Pennsylvania Bureau of Special Education ConsultLine

consultline@odr-pa.org

800-879-2301
ConsultLine is designed to assist parents and advocates of children with disabilities or children thought to be disabled. ConsultLine connects any caller to a special education specialist who can explain federal and state laws relating to special education, describe the options that are available to parents, inform parents of procedural safeguards, identify other agencies and support services, and describe available remedies and how parents can proceed.

Pennsylvania Office of Dispute Resolution

https://odr-pa.org

This office provides the resources for families and educational agencies to resolve educational disputes for children served by the early intervention system, students who are gifted (or thought to be gifted), and students with disabilities (or thought to have disabilities).

Wrightslaw

www.wrightslaw.com
webmaster@wrightslaw.com

Wrightslaw is a website that provides information and support regarding a range of special education, legal issues and policy topics. Additional resources located on the site include books, DVDs, websites and searchable libraries.

PLANNING FOR YOUR EDUCATIONAL FUTURE

As your high school years progress, you, your family and other support people in your life should start to think about your next steps. Although some high schoolers plan to go directly into the workforce, many others choose to continue their educations at trade schools, community colleges, and four-year colleges and universities. Some students are even able to study trades in high school to ease their transition to work. The path you take will be determined by your goals and abilities. Each of these options should be considered as part of your **transition planning**. If you have an IEP, your transition planning should begin in your teen years and continue each year.

You may want to visit CHOP's **Transition to Adulthood Services page** to learn more about how CHOP can support you: *https://www.chop.edu/centers-programs/transition-adulthood-services*

Preparing for Work or Career and Technical Education

Entering the workforce or attending trade school might be more appealing or realistic options for you than a college education. As a worker, you may be entitled to reasonable accommodations to help you do your job. Disabled people are protected at work by the Americans with Disabilities Act (ADA). To learn more about the ADA, check out the "Reasonable Accommodations in the Workplace" fact sheet *(https://adata.org/factsheet/reasonable-accommodations-workplace)* from the ADA Network. This resource can help you understand what a reasonable accommodation is and how to get your employer to give you the accommodations you need.

Workforce Training and Support
Cancer may have affected the way you will function in your workplace. It's important to talk about how you will function as a worker with your high school teachers and service providers (for example, your physical therapist at school) and family members. Consider the strengths you will bring to work, and also the help you may need. Your IEP team may involve direct vocational support, such as a work-study program or a counselor from the Office of Vocational Rehabilitation (OVR), to help you get to work.

Choosing a Career/Technical Program
Investing in career or technical education can be a great way to learn career skills. If the more academic parts of school were difficult for you, the hands-on education in a technical program may be a great fit. Sometimes these programs may also be called "trade school." Some high schools give their students the opportunity to enroll in Career and Technical Education (CTE) programs. High school educators should know what programs in the local community have a good track record of giving students practical skills they need to get great jobs.

This resource from the Federal Trade Commission is a very useful tool. It explains how to make sure the career/technical program you choose is reputable. It provides step-by-step information about how to research and choose a good program for you: *https://www.consumer.ftc.gov/articles/0241-choosing-vocational-school*

College Support for Patients and Survivors

In high school, teachers, case managers, caregivers, and other adults will help you navigate accommodations. In college, the burden shifts onto you. It's your responsibility to **disclose** (tell people about) your disability and to understand and advocate for accommodations. Here are some step-by-step recommendations.

During the College Application Process
When applying to college, think about the kinds of supports you need. For some survivors, being near family and friends is key. You may need to think about the healthcare you need when choosing a campus. Being close to providers is important to some survivors.

Before You Arrive to Campus
Most colleges and universities have an office of disability services. The people who work there help come up with plans for disabled students. The kinds of accommodations you need may be different from those you had in high school. Contact the Office of Disability Services once you have decided on your college or university. It is important to understand what accommodations you will get before classes start. Typically, you will need to provide the office with a letter from a physician stating the reasons you require accommodations.

It is also helpful if you provide your 504 plan or IEP from high school so the person assisting you at the office of disabilities can see what accommodations have worked for you in the past. The United States Department of Education has prepared this document to help you understand your rights as you prepare to transition to college: *https://www.ed.gov/higher-education/students-with-disabilities-preparing-for-postsecondary-education*

Here the Department of Education defines **auxiliary aides** meant to help you access the material in your classes if you have hearing, vision or other sensory impairments: *https://www.ed.gov/laws-and-policy/individuals-disabilities/auxiliary-aids-and-services-for-postsecondary-students-with-disabilities*

Additional Postsecondary Resources

Cancer and Careers
www.cancerandcareers.org
CEW Foundation
159 West 25th Street, 8th Floor
New York, NY 10001
646-929-8032
Provides resources for returning to work after cancer treatment, including tips on writing a resume, job hunting, and making an effective profile on LinkedIn..

Jewish Employment and Vocational Services (JEVS)
www.jevs.org
1845 Walnut Street, 7th Floor
Philadelphia PA 19103
215-854-1800
JEVS Human Services is a not-for-profit nonsectarian social service agency that benefits the community by helping people become more employable and self-sufficient through a broad range of education, training, health and rehabilitation programs. This agency provides employment counseling and assessment, work adjustment counseling, training and job placements for clients with disabilities.

Job Accommodation Network (JAN)
https://askjan.org/
800-526-7234
JAN@AskJAN.org
The JAN is a free consulting service of the Office of Disability and Employment Policy that provides information and one-on-one guidance about job accommodations, the ADA, and the employability of people with disabilities.

Learn to Become
https://www.learnhowtobecome.org/vocational-trade-schools/
Defines career and technical education, lists pros and cons of pursuing career and technical education, describes different opportunities and educational routes, and provides guidance on considerations when selecting and applying to schools.

New Jersey Division of Vocational Rehabilitation Services (NJ DVRS)
https://nj.gov/labor/career-services/special-services/individuals-with-disabilities/
1 John Fitch Plaza, PO Box 398
Trenton, NJ 08625-0398
866-871-7867, 609-292-5987 (within NJ)
New Jersey DVRS provides services that enable individuals with disabilities to find jobs or keep their existing jobs.

Office of Vocational Rehabilitation (OVR)
https://www.pa.gov/agencies/dli/programs-services/disability-and-vocational-rehabilitation/individualized-employment-services0.html

The OVR's mission is to help Pennsylvanians with disabilities obtain and maintain employment and independence. The website features specific links to find local service organizations in greater Philadelphia, the Lehigh Valley, Northeastern PA, Susquehanna Valley, Central PA, Northwest PA and Greater Pittsburgh. Resources for workers' rights under law are also explained. A database of employment opportunities can also be accessed from this site.

Pennsylvania Department of Education: Career and Technical Education
https://www.pa.gov/agencies/education/programs-and-services/instruction/elementary-and-secondary-education/career-and-technical-education.html

Provides information on Career and Technical Education programs that are approved by the Pennsylvania Department of Education. Many of these programs are available for current high school students but may also provide continuing education for young adult learners.

State of New Jersey Department of Education: Career and Technical Education
https://www.nj.gov/education/cte/

Provides information on secondary and postsecondary career and technical programs aligned to New Jersey's key industries.

FINANCIAL, TRANSPORTATION, AND LEGAL RESOURCES FOR SURVIVORS

National Financial Resources

Cancer treatment and the late effects of treatment can have a significant impact on the finances of young adult survivors. In this section, you will find national resources that may be helpful for you if you are in need of financial assistance related to employment, treatment for late effects, health insurance or other issues you may be facing.

Leukemia & Lymphoma Society: Cancer and Your Finances
https://www.lls.org/booklet/cancer-and-your-finances

This online booklet describes health insurance options and resources that may help you and your family cope with the financial aspects of cancer care.

Medicine Assistance Tool (MAT)
https://medicineassistancetool.org/

PhRMA's MAT is a search engine for many of the patient assistance resources offered by the biopharmaceutical industry.

Patient Advocate Foundation (PAF)
https://www.patientadvocate.org
800-532-5274
PAF is a national nonprofit organization that provides assistance to cancer patients and survivors about healthcare, insurance, financial issues, job discrimination and debt crisis matters. They also have a Co-Pay Relief program that provides limited payment assistance for prescriptions for those who financially and medically qualify. For more information about the Co-Pay Relief Program, visit www.copays.org or call 1-866-512-3861.

The Samfund
http://www.thesamfund.org/
617-938-3484
info@thesamfund.org
The Samfund is national nonprofit organization that provides direct financial assistance as well as online support and education for young adult cancer survivors (ages 21-39) to move forward toward their personal, professional and academic goals.

Financial Resources for New Jersey Residents

Catastrophic Illness in Children Relief Fund Commission
New Jersey Department of Human Services
P.O. Box 728, Trenton, NJ 08625-0728
609-292-0600
https://www.nj.gov/humanservices/cicrf/

The Catastrophic Illness in Children Relief Fund is a program for New Jersey families that provides financial assistance for potentially catastrophic medical expenses due to a child's illness or condition. To be eligible, the child must have been 21 years or younger when the medical expenses occurred; have residence in New Jersey for three months immediately prior to date of application; and in any prior, consecutive, 12-month period, dating back to 1988, eligible expenses must exceed 10 percent of the family's income, plus 15 percent of any excess income over $100,000.

New Jersey Family Care Program/ Medically Needy Program
https://njfamilycare.dhs.state.nj.us/

This program provides limited health coverage to children under the age of 21 who do not qualify for regular NJ Medicaid because their family income or financial resources are too high. Available to families who have been denied for SSI and who do not have employer-provided insurance.

Transportation Assistance

Modivcare of New Jersey (formerly Logisticare Medical Transportation)
https://www.nj.gov/humanservices/dmahs/clients/medical-transportation/

1-866-527-9933

Logisticare is the provider for Medical Assistance transportation for the state of New Jersey. If you are a recipient of NJ Family Care/Medicaid and need a ride to a non-emergency medical appointment, you can call the number above at least two days before you need the ride. Reservations can also be made online at: *https://www.modivcare.com/facilities/nj/*

Medical Assistance Transportation Program (MATP) (Pennsylvania)
https://www.pa.gov/services/dhs/medical-assistance-transportation-program.html

Pennsylvania's MATP is a transportation service available to people receiving Medical Assistance paid for by the state. The program provides paratransit to people with disabilities, mileage reimbursement or public transportation. Each county has its own application process, so be sure to call your county's provider well ahead of your first appointment date to register for the ability to arrange rides.

Road to Recovery
https://www.cancer.org/treatment/support-programs-and-services/road-to-recovery.html

800-227-2345

The American Cancer Society Road to Recovery program provides transportation to and from treatment for people with cancer who do not have a ride or are unable to drive themselves. This program is available nationwide and will match volunteer drivers with patients, so it is dependent on volunteer availability. Be sure to call well in advance of your appointment for the best chance of being matched with a driver.

Other Legal Information

These organizations assist survivors and individuals with disabilities with education and resources about their legal rights.

Cancer Legal Resource Center (CLRC)
https://thedrlc.org/cancer/

866-THE-CLRC (843-2572)

info@theDRLC.org

The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, employers and others coping with cancer.

Disability Rights Pennsylvania (DRP)
https://www.disabilityrightspa.org/

Philadelphia office:
1800 JFK Boulevard, Suite 900,
Philadelphia, PA 19103
215-238-8070

DRP is an independent, statewide, nonprofit corporation designated as the federally mandated protection and advocacy agency in Pennsylvania. DRP provides help to Pennsylvanians with disabilities who are experiencing problems or who have questions related to their disability. That help can include information, referral to other organizations, advocacy and legal action. DRP also offers a number of self-advocacy guides on its website on topics including education, employment, healthcare, mental health and more.

National Cancer Legal Services Network (NCLSN)
https://legalhealth.org/nclsn/

NCLSN promotes increased availability of free legal services programs so that people affected by cancer (patients, families and caregivers) may focus on medical care and their quality of life. Their website has a service directory that lists office locations where you can find legal help for issues you may face as a result of your diagnosis and treatment.

Patient Legal Handbook
https://thedrlc.org/cancer/

This handbook, available in English and Spanish, is a resource for patients coping with cancer and provides valuable information about cancer-related legal issues from diagnosis through survivorship. Topics include paying for medical care and how to work through financial and employment issues.

U.S. Department of Justice ADA Information Line, Civil Rights Division
www.ada.gov/infoline

800-514-0301
800-514-0383 (TTY)

This is a toll-free information line that provides information related to the Americans with Disabilities Act (ADA). By calling this line, you can speak with an ADA specialist, who can assist you in understanding how the ADA applies to your situation.

LAWS RELATED TO EMPLOYMENT ISSUES

The following laws protect individuals with disabilities and special healthcare needs from employment-related discrimination.

Americans with Disabilities Act (ADA)
(ADA; 42 U.S.C. 12101 et seq.)

www.ada.gov

ADA Information Line
800-514-0301 (voice)
800-514-0383 (TTY)

The ADA prohibits some types of job discrimination by employers, employment agencies and labor unions against people who have or have had cancer. Whether a cancer survivor is covered by the ADA is decided on a case-by-case basis. Cancer survivors who need extra time or help to work are entitled to a "reasonable accommodation." The ADA does not prohibit an employer from ever firing or refusing to hire a cancer survivor. Because the law requires employers to treat all employees similarly, regardless of disability, an employer may fire a cancer survivor who would have been terminated even if he or she was not a survivor.

Employee Retirement and Income Security Act (ERISA; 29 U.S.C. 1001 et seq.)
https://www.dol.gov/general/topic/health-plans/erisa

This law prohibits an employer from discriminating against an employee to prevent him or her from collecting benefits under an employee benefit plan.

Equal Employment Opportunity Commission (EEOC)
www.eeoc.gov

1-800-669-4000
1-800-669-6820 (TTY)
1-844-234-5122 (ASL video phone for deaf/hard of hearing callers only)

info@eeoc.gov

The EEOC is responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information.

Information obtained from the National Cancer Policy Board (2003) Childhood Cancer Survivorship: Improving Care and Quality of Life. Available: www.nap.edu/catalog.php?record_id=10767

Family Medical Leave Act
(FMLA; 29 U.S.C. 2601 et seq.)

https://www.dol.gov/agencies/whd/fmla

The FMLA reasonably balances the needs of the employer and employee. It requires employees to make reasonable efforts to schedule foreseeable medical care so as to not unduly disrupt the workplace; requires employees to give employers 30 days' notice of foreseeable medical leave, or as much notice as possible; allows employers to require employees to provide certification of medical needs; allows employers to seek a second opinion, at the employer's expense, to corroborate medical need; and permits employers to provide more leave time than required by the FMLA.

Relevant Federal Laws

Five federal laws provide survivors some opportunities to keep health insurance that they obtain through work.

The Affordable Care Act (2010)

https://www.healthcare.gov/health-care-law-protections/

https://www.healthcare.gov/downloads/apply-for-or-renew-coverage.pdf

Insurance companies can no longer limit or deny benefits to children/adolescents under the age of 19 due to a pre-existing health condition. Young adults under the age of 26 can be covered under their parent's health plan even if they are married, not living with their parents, attending school, not financially dependent on parents, and eligible to enroll in their employer's plan. See link for accessing the marketplace for insurance.

Americans with Disabilities Act
(ADA; 42 U.S.C. 12101 et seq.)

www.ada.gov

ADA Information Line
800-514-0301 (voice)
800-514-0383 (TTY)

Prohibits employers from denying health insurance to cancer survivors if other employees with similar jobs receive insurance. Does not require employers to provide health insurance, but when they choose to provide health insurance, they must do so fairly.

Continuation of Health Coverage – The Consolidated Omnibus Budget Reconciliation Act of 1986
(COBRA; PL 99-272)

https://www.dol.gov/general/topic/health-plans/cobra

COBRA requires employers to offer group medical coverage to employees who otherwise would have lost their group coverage due to individual circumstances. Public and private employers with more than 20 employees are required to make insurance coverage available to employees who quit, are terminated or work reduced hours. Coverage must extend to surviving, divorced, or separated spouses and to dependent children.

By allowing survivors to keep group insurance coverage for a limited time, COBRA provides valuable time to look for long-term coverage. The survivor must pay for the continued coverage, which may include the cost the employer previously paid, plus a 2 percent administrative charge.

Employee Retirement and Income Security Act
(ERISA; 29 U.S.C. 1001 et seq.)

https://www.dol.gov/general/topic/health-plans/erisa

Prohibits an employer from discriminating against an employee to prevent him or her from collecting benefits under an employee group benefit plan. Employee benefit plans that are self-insured are regulated only by federal law, not state insurance law.

Health Insurance Portability and Accountability Act (HIPAA)

https://www.hhs.gov/hipaa/for-individuals/index.html

HIPAA helps cancer survivors retain their health insurance. It allows individuals who have been insured for at least 12 months to change to a new job without losing coverage, even if they previously have been diagnosed with cancer.

For previously uninsured individuals, group plans cannot exclude them due to a pre-existing medical condition of more than 12 months for conditions for which medical advice, diagnosis, or treatment was received within the previous six months.

Federal Health Insurance and Disability Programs

Medicare Disability Program

https://www.ssa.gov/disabilityresearch/wi/medicare.htm

Medicare eligibility is expanded to include certain disabled individuals under the age of 65. Non-elderly individuals who have received Social Security Disability Insurance (SSDI) payments for 24 months are eligible. Eligible individuals must have limited income and resources and a physical or mental impairment that is expected to last 12 months or result in death.

Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/

EPSDT is a benefit of Medicaid. This benefit provides comprehensive and preventive healthcare services for children under age 21 who are enrolled in Medicaid. These include appropriate preventive, dental, mental health, developmental, and specialty services.

Medicaid and State Children's Health Insurance Program (S-CHIP)

www.medicaid.gov

Medicaid is insurance for individuals who are low income or disabled and that is generally accessed through the state they live in. Rules on eligibility for Medicaid vary from state to state. Medicaid sometimes pays transportation and prescription costs.

Supplemental Security Income (SSI)

www.ssa.gov

Philadelphia Region: *www.ssa.gov/phila*
New York Region: *www.ssa.gov/ny*

SSI is a federally funded program that provides monthly payments to individuals who are elderly, blind, or are children or adults with disabilities. Eligibility depends on your family income. Apply at your local Social Security Administration office or call 1-800-SSA-1213.

Online Health Insurance Information

As a cancer survivor, having health insurance is very important so you can continue following up with your healthcare team. Some survivors may qualify for health insurance programs that are funded by their state or other sources.

HealthCare.gov

https://www.healthcare.gov

At healthcare.gov, you can learn about insurance options available through the Affordable Care Act, as well as enroll in health insurance coverage and change or manage your plans. This website is managed by the U.S. Department of Health and Human Services.

Healthcare Marketplace

https://www.healthcare.gov/marketplace-in-your-state/

Provides assistance with applying for coverage and comparing coverage in your state.

Medical Assistance in Pennsylvania (MA)

https://www.pa.gov/agencies/dhs/resources/medicaid.htm

MA, also known as Medicaid, is a state program that pays for healthcare services for eligible individuals. In Pennsylvania, children 18 and younger with serious disabilities are eligible for MA regardless of their parents' income. This means that even children whose parents' income is too high for SSI still qualify for Medicaid. For children who are already insured, Medicaid becomes a secondary policy that will cover expenses that are not covered by the primary policy. To apply, contact your local County Assistance Office (CAO) or apply online using the COMPASS website (www.compass.state.pa.us).

National Coalition for Cancer Survivorship (NCCS)

https://www.canceradvocacy.org/

8455 Colesville Road, Suite 930, Silver Spring, MD 20910
877-NCCS-YES
info@canceradvocacy.org

NCCS's mission is to advocate for quality cancer care for all people touched by cancer. Their publication, "What Cancer Survivors Need to Know About Health Insurance," details types of health insurance, personal rights, how to use your healthcare coverage, and where to find health and information. Access the publication at *https://canceradvocacy.org/wp-content/uploads/2013/01/Health-Insurance.pdf*

Pennsylvania Health Law Project

www.phlp.org

1-800-274-3258
staff@phlp.org

The Pennsylvania Health Law Project's helpline is available to provide free information, advice, and direct representation to people having trouble accessing healthcare coverage and services through publicly funded healthcare programs such as Medicaid and CHIP.

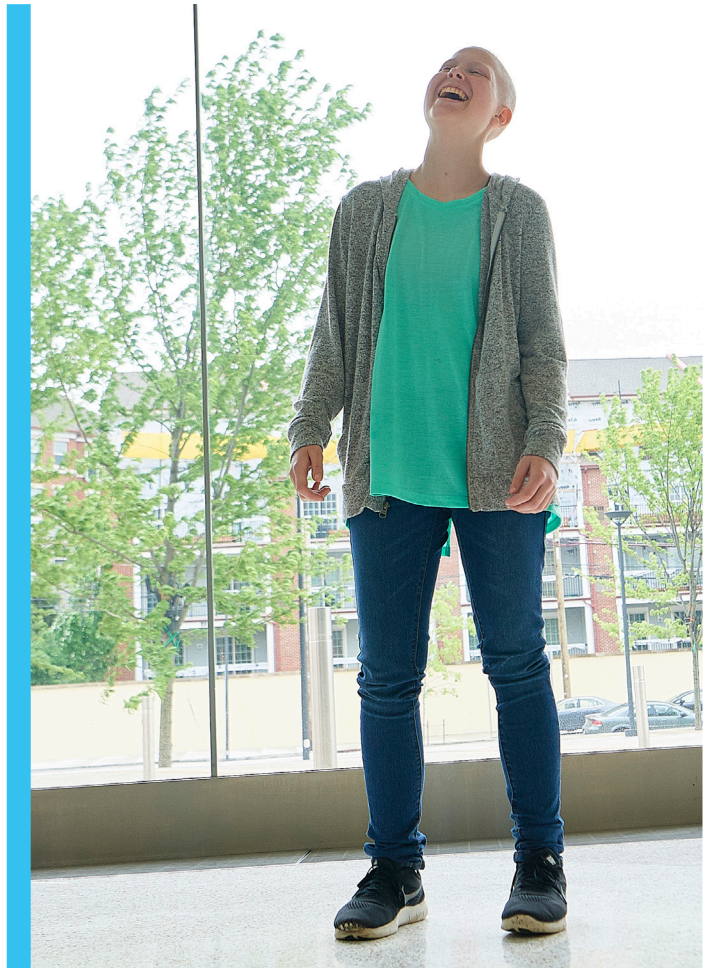
GROUPS AND ORGANIZATIONS PROVIDING SUPPORT, EDUCATION AND/OR ADVOCACY

CHOP Resources

Adolescent & Young Adult (AYA) Oncology Program Email List and Events

https://www.chop.edu/pages/services/adolescent-young-adult-oncology-program

Sign up to receive updates from the AYA at CHOP. Please follow the above link to fill out a form or ask your social worker to add your email to the distribution list.
*This email group is *not* a way to discuss any clinical concerns. These should be addressed directly with your clinical team members.



AYA FAQs (PDF)

https://media.chop.edu/data/files/pdfs/aya-qa-brochure.pdf

If you are an adolescent or young adult (AYA) with cancer, you probably have many questions. We understand that not everyone wants to ask their questions out loud, so we've compiled a list of those that are often asked.

Local Groups and Organizations

These groups and organizations are located in Pennsylvania, New Jersey and Delaware, and offer in-person and online services for AYA survivors who live in the area.

CancerCare of New Jersey

https://www.cancercare.org/contact/new_jersey

1 Kalisa Way, Suite 205, Paramus, NJ 07652
201-444-6630 or 1-800-813-HOPE (4673)

njinfo@cancercare.org

CancerCare is a national organization that provides free support services to anyone affected by cancer, including survivors, caregivers, children, loved ones and the bereaved. CancerCare programs, which include counseling, education and practical help, are all provided by trained oncology social workers and are free of charge.

Cancer Support Community/Gilda's Club

https://www.cancersupportcommunity.org/

The Cancer Support Community and Gilda's Club provide resources, as well as social and emotional support for those who have cancer or have survived cancer. Services include support groups, stress management, education programs, nutrition workshops and social events. They also have an extensive program for children and teens.

Cancer Support Community of Greater Lehigh Valley

https://www.cancersupportglv.org/

944 Marcon Blvd., Suite 110,
Allentown, PA 18109
610-861-7555

Cancer Support Community of Greater Philadelphia

www.cancersupportphiladelphia.org/

4100 Chamounix Drive
Philadelphia, PA 19131
215-879-7733

Crossroads4Hope

https://crossroads4hope.org

3 Crossroads Drive
Bedminster, NJ 07921
908-658-5400
info@crossroads4hope.org

Cancer Support Community New Jersey at Gilda's Club

https://www.cscnj.org/

700 New Road
Linwood, NJ 08221
609-926-2699

Cancer Bridges *(formerly Our Clubhouse)*

https://cancerbridges.org/

2816 Smallman Street
Pittsburgh, PA 15222
412-338-1919

Cancer Bridges (formerly *Our Clubhouse*) connects families to resources within their community to allow children and youth with special healthcare needs to be successful and develop to their full potential.

Ocean of Love

https://oceanoflove.org/

1709 Route 37E
Toms River, New Jersey 08753
732-270-3500

Ocean of Love is an organization that serves children with cancer and their families who live in Ocean County, NJ. They have a support group for teen and young adult survivors, who are on or off treatment, that meets monthly.

Special Kids Network (SKN) of PA

https://www.pa.gov/agencies/health/programs/healthy-living/special-kids-network.html

1-800-986-4550

The SKN helpline assists providers and parents of children and youth with special healthcare needs access local services and supports. SKN serves children and youth with physical, developmental, behavioral or emotional needs from birth through age 21.

Young Survival Coalition

www.youngsurvival.org

405 Lexington Avenue, 26th Floor
New York, NY 10174
877-972-1011

The Young Survival Coalition serves adolescents and young adults currently facing or who have survived breast cancer. The site provides information about maintaining a healthy lifestyle and managing your healthcare, as well as support and advocacy programs.

National Groups and Organizations

The following websites and organizations offer support and opportunities for survivors across the country.

13thirty Cancer Connect

www.13thirty.org

The mission of 13thirty Cancer Connect is to help adolescents and young adults with cancer live their very best lives. The organization helps AYA survivors build a new peer community of others who understand. They offer programs on fitness, nutrition and art for teens, young adults, and parents.

American Association for Cancer Research (AACR)

https://www.aacr.org/patients-caregivers/patient-advocacy/

615 Chestnut Street, 17th Floor
Philadelphia, PA 19106

AACR's Survivor and Patient Advocacy Program is dedicated to creating partnerships between cancer survivors, patient advocates and scientific communities to inform scientific discovery, public policy and clinical research. If you are interested in becoming a patient advocate or participating in any other opportunities offered by this program, applications are available at the website.

American Cancer Society: Cancer Survivors Network (CSN)

https://csn.cancer.org

The CSN is a community that provides information for survivors about being healthy after treatment, ongoing research, and local resources for help. Survivors and families can connect with one another through online chats and message boards, as well as support groups.

American Cancer Society: National Cancer Information Center

https://www.cancer.org/about-us/online-help/contact-us.html

1-800-227-2345

Not sure where to find what you need? American Cancer Society's National Cancer Information Center connects patients and families with all kinds of resources 24 hours a day, 7 days a week.

American Childhood Cancer Organization

http://www.acco.org

855-858-2226

The American Childhood Cancer Organization provides information on late effects that survivors may experience as well as support and advocacy information. This is a self-help network for parents of children with cancer. Services include support from other families, reading materials, a quarterly newsletter for parents and professionals, and a newsletter for children.

Boarding for Breast Cancer

http://www.b4bc.org

This organization raises awareness about breast cancer, the importance of early detection and the value of an active lifestyle through youth-focused educational programs and fundraising.

CancerClimber Association (CCA)

www.cancerclimber.org

PO Box 443
Littleton, CO 80160

info@cancerclimber.org

The CCA provides experiential and motivational adventures and excursions such as extreme mountain climbing and summit tours. The CCA also offers Adventure Support Grants to cancer survivors to fund their own adventures.

Cancer.net

https://www.cancer.org/cancer/survivorship.html

800-227-2345
contactus@cancer.net

Cancer.net has resources and information focusing on survivorship, steps to take after cancer, information about late effects and rehabilitation. The site also offers a Guide to Survivorship from the American Society of Clinical Oncology in English and Spanish.

Cervivor

www.cervivor.org

info@cervivor.org

Raises awareness about cervical cancer and its link to the human papillomavirus through a network of survivors and their friends.

Children's Cancer Cause

www.childrenscancercause.org

202-552-7392

Children's Cancer Cause is a national advocacy organization working to achieve more effective treatment for pediatric cancer patients and to address the unique needs and challenges of childhood cancer survivors and their families. It empowers survivors and families with educational materials and tools to improve their quality of life and become effective advocates for themselves and for others.

Children's Oncology Group

http://www.survivorshipguidelines.org/

The Children's Oncology Group provides guidelines and recommendations to healthcare professionals about long-term follow-up for cancer survivors. Although the information within the guidelines may be valuable to the survivors themselves, the only version currently available is targeted to healthcare professionals. Therefore, survivors who choose to review these guidelines are strongly encouraged to do so with the assistance of a healthcare professional knowledgeable about long-term follow-up care for survivors of childhood, adolescent and young adult cancers.

College Consultants Care

http://www.collegeconsultantscare.org

919-607-1265

College Consultants Care provides free college application assistance from experienced Independent Educational Consultants to students diagnosed with cancer (and who are in treatment) or have a parent diagnosed with cancer.

Colon Club

www.colonclub.com

Colon Club raises public awareness of colorectal cancer for young adults in creative ways by educating those in need about risk factors, symptoms and screenings.

CureSearch for Children's Cancer (formerly National Childhood Cancer Foundation)

www.curesearch.org

1-800-458-6223
info@curesearch.org

The website provides information for cancer patients at all stages of treatment and survivorship. Information is available for patients, families and communities.

Elephants and Tea

www.elephantsandtea.com/

Elephants and Tea is a media company with the mission to help AYA patients, survivors and caregivers know they are not alone in their fight with cancer. The company publishes a quarterly magazine written for and by the AYA cancer community. The magazine contains stories written by current patients as well as those in survivorship, detailing life after cancer. Current and past digital issues are available on the website.

GET EMPOWERED: Life, Living & Follow-Up Care After Cancer

https://www.cancer.northwestern.edu/cancer-care/survivorship/star-program/get-empowered.html

Videos available on Youtube: *https://www.youtube.com/playlist?list=PLJYcr5PhvvTtt-aASjcsSTen1zHpV_PWf*

GET EMPOWERED is a video education series for childhood cancer patients and long-term survivors. The series includes videos on the following topics: Introduction to childhood cancer and its impact on adult survivors; transitioning to adult healthcare; cardiac risk factors; prevention and late effects; fertility; finding a "new normal"; and navigating the emotional side of survivorship.

The videos feature seven survivors sharing their own experiences, as well as survivorship care providers contributing their expertise. They emphasize the cancer journey, and each video ends with a list of relevant resources.

Lacuna Loft (Now *Cactus Cancer Society*)

https://cactuscancer.org/

Cactus Cancer Society (formerly know as Lacuna Loft) is a nonprofit organization providing online support programs to young adult cancer patients, survivors and caregivers. The organization offers many online programs so young adult cancer survivors can access them and connect to peers from anywhere. They strive to make sure that survivorship support is available, accessible and specifically designed for young adults facing cancer.

Leukemia & Lymphoma Society (LLS)

www.lls.org/

800-955-4572

The LLS has local chapters throughout the U.S. and Canada that hold events and have patient support services (see below for details on the PA, NJ, and DE chapters). The LLS provides financial assistance, education, and emotional support services, and has resources specific to the needs of young adult survivors, such as the LLS Discussion Boards.

One of their discussion boards is an online chat group called YAconnect: young adults living with Leukemia, Lymphoma and Myeloma. The purpose of this chat group is to provide a forum for young adult patients (ages 18-39) to address the stresses and triumphs shared by those living with leukemia, lymphoma or myeloma. This chat group is open for you to discuss any issue related to living with leukemia, lymphoma or myeloma. YAconnect is every Tuesday evening, 8:30 p.m. to 10:30 p.m. EST.

Eastern PA - Delaware Chapter

https://www.lls.org/epa-de

610-238-0360
100 N. 20th Street Suite 405
Philadelphia, PA 19103

Eastern Great Lakes Chapter

https://www.lls.org/egl

333 E. Carson St., Ste 441
Pittsburgh, PA 15219

New Jersey Chapter

https://www.lls.org/nj

908-956-6600
14 Commerce Drive
Cranford, NJ 07016

Patti Robinson Kaufmann First Connection Program

https://www.lls.org/support/peer-to-peer-support

This program matches patients with blood cancers and their families with trained peer volunteers in their area. To be matched or to volunteer, visit the above website, contact your local Leukemia & Lymphoma Society office, or call the main center at 800-955-4572.

Survivorship Website

https://www.lls.org/children-and-young-adults/young-adults/survivorship

The Leukemia & Lymphoma Society's survivorship website offers information and guidelines about what to expect and how to handle life after cancer.

Livestrong Fertility

https://livestrong.org/how-we-help/livestrong-fertility/

855-220-7777

Livestrong Fertility has resources to help cancer patients and survivors understand their fertility risks and options and get access to fertility preservation discounts.

Livestrong Foundation

www.livestrong.org

877-236-8820

This foundation, started by Lance Armstrong, provides information about managing the physical and emotional effects of cancer and its treatment. The website has helpful guides and worksheets, and stories from other survivors.

Mayo Clinic

www.mayoclinic.org

Part of Mayo Clinic's mission is to provide reliable health information. The following websites provide up to date medical information and research that can help patients and survivors understand their diagnoses, treatment and late effects.

Cancer survivors: Care for your body after treatment

https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20044015

Cancer survivors: Late effects of cancer treatment

https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20045524

Cancer survivors: Managing your emotions after cancer treatment

https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20047129

Cancer survivors: Reconnecting with loved ones after treatment

https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20045378

National Brain Tumor Society

https://braintumor.org/support-services/toolkit/

The National Brain Tumor Society provides a web community to support patients and survivors of brain tumors as well as their friends and families. The site helps locate support and provides resources specifically for adolescents and young adults who have survived a brain tumor.

National Cancer Institute Office of Cancer Survivorship (OCS)

https://cancercontrol.cancer.gov/ocs/resources/survivors-caregivers-advocates

1-800-422-6237

NCIinfo@nih.gov

OCS funds research on survivorship issues. OCS is dedicated to developing databases and researcher networks that support the follow-up needed to study long-term survivors. OCS also supports programs to educate patients, physicians and the public about cancer survivorship. This site contains information about health and wellbeing after cancer, as well as information about possible late effects, and links to supportive resources.

National Children's Cancer Society (NCCS)

www.thenccs.org

500 North Broadway, Suite 1850
St Louis, MO 63102
314-241-1600

The mission of the NCCS is to improve the quality of life for children with cancer and their families by providing financial assistance, advocacy, support and education. Other resources provided include online support, college scholarships for survivors and teleconferences about issues related to survivorship, such as fertility concerns and insurance issues.

National Coalition for Cancer Survivorship

www.canceradvocacy.org

8455 Colesville Road, Suite 930
Silver Spring, MD 20910
877-NCCS-YES

info@canceradvocacy.org

The National Coalition for Cancer Survivorship is a survivor-led cancer advocacy organization working for quality cancer care for all Americans and empowering cancer survivors. The group organizes Cancer Advocacy Now!, a legislative advocacy network that engages people across the country in federal cancer-related issues. The website has many resources for patients in treatment and survivors including the Cancer Survival Toolbox and Survivorship Checklist, and more.

National Collegiate Cancer Foundation (NCCF)

http://collegiatecancer.org/survivorship

8334 North Brook Lane
Bethesda, MD 20814
240-515-6262

info@collegiatecancer.org

The NCCF helps cancer survivors reach their goals for higher education. The NCCF provides need-based financial support for academic costs throughout treatment and beyond. The NCCF works to promote awareness of cancer in the young adult community while helping with the transition from being a patient to being a survivor.

National Grace Foundation

https://graceamerica.org/

401-793-6337

info@graceamerica.org

The National Grace Foundation provides free college admissions and financial aid assistance to young cancer fighters and their families.

Next Step

www.nextstepnet.org

99 Bishop Allen Drive
Cambridge, MA 02139
617-864-2921
info@nextstepnet.org

Next Step provides in-person support, education, and resources for young people coping with serious illness. Face2Face was designed for young adults with cancer and organizes in-person communities during weekend retreats and workshops. Face2Face provides life skills and wellness workshops.

Patient Advocate Foundation (PAF)

www.patientadvocate.org

421 Butler Farm Road
Hampton, VA 23666
1-800-532-5274

The PAF provides education, legal counseling and referrals to cancer survivors concerning managed care, insurance, financial issues, job discrimination and debt crisis. The Co-Pay Relief Program provides payment assistance for medicine to patients.

Pediatric Brain Tumor Foundation

https://curethekids.org/resource/support-for-families/

Pediatric Brain Tumor Foundation offers many resources to pediatric brain tumor patients and their families. The organization offers peer-to-peer mentoring as well as a free survivorship guidebook. The guidebook includes tools to help manage your medical care as a survivor, templates and forms to track treatment and follow-up care for your brain tumor, and information about how to stay healthy mentally and physically.

Re-Mission 2

www.re-mission2.org/

A free 3D shooter video game designed for adolescents and young adults with cancer and survivors. Players control a nanobot who battles cancer and bacterial infections, and manages realistic, life-threatening side effects associated with the disease.

Rethink Breast Cancer

www.rethinkbreastcancer.com

50 Carroll St.
Toronto, Ontario
Canada M4M 3G3
416-220-0700

Rethink Breast Cancer provides support for young adults affected by breast cancer. Survivors can volunteer to provide peer support to young women recently diagnosed with breast cancer.

SaveMyFertility

https://www.savemyfertility.org/

965 Wilson Road, Room A626B
East Lansing, MI 48824-1316
517-884 8848

oncofert@msu.edu

This website provides information about fertility concerns after completion of cancer treatment and provides numerous resources about fertility issues that arise as a result of cancer treatment.

Sean Kimerling Testicular Cancer Foundation

www.seankimerling.org

This organization is dedicated to increasing early detection of testicular cancer and providing information on regular self-examination.

Sharsheret

www.sharsheret.org

866-474-2774
info@sharsheret.org

Sharsheret is a survivor-led national organization dedicated to addressing the unique concerns of young Jewish women facing or having survived breast or ovarian cancer. It offers opportunities to connect with other young survivors, join a peer support network and attend informative webinars that address a variety of topics.

Stupid Cancer

www.stupidcancer.org

40 Worth St., Suite 808
New York, NY 10013
212-619-1040

contact@stupidcancer.org

Stupid Cancer offers a lifeline to the young adult cancer community by connecting them to age-appropriate resources and peers who get it. Their mission is to empower adolescents and young adults affected by cancer by ending isolation and building community. They also hold an annual conference, CancerCon.

Teen Cancer America

https://teencanceramerica.org/

11845 Olympic Blvd. #775 W
Los Angeles, CA 90064
310-208-0400

Teen Cancer America's mission is 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.

Triage Cancer

www.triagecancer.org

6348 N. Milwaukee Ave. #136
Chicago, IL 60646
424-258-4628

info@triagecancer.org

Triage Cancer is a national, nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, quick guides and cancer resources.

Ulman Foundation

www.ulmanfoundation.org

1215 East Fort Avenue, Suite 104
Baltimore, MD 21230
1-888-393-FUND (3863)

info@ulmanfoundation.org

The Ulman Cancer Fund provides a comprehensive support program for young adults affected by cancer. It offers social support services and resources such as, Survival Guide: "No Way It Can't Be! A Guidebook for Young Adults Facing Cancer."

Vital Options International

www.vitaloptions.org/

800-518-2354

Vital Options International is an organization designed to create discussion about chronic, terminal and rare conditions, so people around the world can share their stories, support and resources.

Camps/Outdoor Experiences

This section lists camps and organizations that provide outdoor experiences. If you would like the most up-to-date information or availability of camping opportunities, please reach out to your CHOP social worker.

Camp Mak-A-Dream

https://www.campdream.org/camps-programs/young-adult-conference/

P.O. Box 1450
Missoula, MT 59806

406-549-5987

Camp Mak-A-Dream offers two different educational programs for young adults which are cost-free and medically supervised. The Young Adult Conference (YAC) is a unique program designed for those who have been diagnosed with cancer and offers a place for them to meet, learn, share and have fun. The other program offered is the Head's Up Conference designed specifically for young adult survivors of brain tumors who are dealing with long-term effects of both their disease and its treatment. Both conferences offer education workshops and recreational activities like hiking, swimming, art activities and soaking in a hot tub.

Camp Simcha

https://www.campsimcha.org/

151 West 30th Street
Third Floor
New York, NY 10001
212-699-6661, 877-CHAI-LIFE

camp@chailifeline.org

Camp Simcha is a kosher camp open to adolescents and young adults up to age 20 in active treatment or posttreatment for cancer and other life-threatening illnesses, located on 125 acres in Glen Spey, New York. The camp is one of the many services provided by Chai Lifeline.

Camp Sunshine

http://www.campsunshine.org/

35 Acadia Road
Casco, ME 04015
207-655-3800

info@campsunshine.org

This camp provides respite, professional counseling and recreational opportunities for families facing the physical, emotional and financial strain of a child with a critical illness. (Child with cancer must be 18 or younger and within five years of their cancer treatment.)

First Descents

www.firstdescents.org/

3858 Walnut St., Suite 161
Denver, CO 80205
303-945-2490

info@firstdescents.org

First Descents provides opportunities for young adult cancer survivors to experience the excitement of kayaking, rock climbing and other outdoor adventures. No previous experience is required. The adventures may be challenging, but they are also safe for patients and survivors. Programs are free of charge for first-time participants. All cancer fighters and survivors ages 18-39 are eligible.

River Discovery

www.riverdiscovery.org

PO Box 8336
Boise, ID 83707
208-303-0040
info@riverdiscovery.org

This organization provides adventure programs, including a teen trip for cancer survivors on the Salmon River: six days of rafting, camping, hiking and exploring.

Ronald McDonald Camp

https://www.rmhcphilly.org/camp/

camp@rmhcphilly.org

This is an overnight camp for kids with cancer (up to age 17) and their siblings. It's run by CHOP's Oncology division staff and provides 24-hour on-site medical coverage.

Survivor Summit

https://www.survivorsummit.org/summit

Survivor Summit for young adult cancer survivors, founded in 2011, began as an adventure taking cancer survivors to summit Mount Kilimanjaro. Survivor Summit is now an annual week-long adventure for cancer survivors age 18 and older, held at the Echo Hill Outdoor School on the Chesapeake Bay in Maryland.

True North Treks

www.truenorthtreks.org

info@truenorthtreks.org

Dedicated to enriching the lives of adolescent and young adult cancer survivors through contemplative and outdoor-based activities.

Mentorship/Peer Counseling/Emotional Support

These are national organizations that provide mentorship, peer counseling or emotional support.

BMT InfoNet's Caring Connections Program

https://bmtinfonet.org/caring-connections

1548 Old Skokie Road, Suite 1
Highland Park, IL 60035
888-597-7674

This program matches current bone marrow transplant patients and caregivers with survivors and caregivers who have been through transplant and can offer nonmedical information and emotional support. Request support or sign up to volunteer at the link above.

Cancer Support Helpline available through Cancer Support Community

https://www.cancersupportcommunity.org/cancer-support-helpline

1-888-793-9355
Live chat option available online

The Cancer Support Helpline offers free support and coaching for cancer patients and their loved ones. Professional counselors and navigators provide medical information, emotional support and resource referrals to callers nationwide.

Children's Brain Tumor Foundation's Family 2 Family Program

https://cbtf.org/connect/

212-448-9494
info@cbtf.org

This program matches parents and survivors (18 years and older) of brain tumors with trained mentor parents and survivors. Applications for parents and survivors who wish to become mentors are online.

Imerman Angels

www.imermanangels.org/

205 W. Randolph, 19th Floor
Chicago IL 60606
866-IMERMAN (463-7626)

Imerman Angels provides one-to-one support by matching a person who has experienced cancer (either a fighter or a survivor) with a Mentor Angel, who has fought and survived the same type of cancer. The one-on-one relationships offer the chance to ask personal questions and receive support from someone who is uniquely familiar with the experience. To sign up for this peer-to-peer support service, go to the website or call the number above. Additional connections are offered to caregivers, including friends, parents, siblings, and spouses. Services are free and available to anyone at any stage of cancer and at any age.

Young Adult Cancer Connection

https://www.yacancerconnection.org

Young Adult Cancer Connection offers young adults (18-39) with cancer experience, whether in remission or in treatment, and their caregivers a forum to work through the issues unique to this age group.

HEALTH PROMOTION INFORMATION AND RESOURCES

Digital Health Tools (e.g., Apps and Websites) and Patient Portals

myCHOP

https://mychop.chop.edu/

With CHOP's patient portal you can schedule appointments, access records, see test results, ask your care provider questions and more — right from your smartphone or computer.

Cancer SurvivorLink™

www.cancersurvivorlink.org

SurvivorLink is a website that stores your Survivor Healthcare Plan (SHP) in a Patient Portal, letting you see your treatment summary, risk for late effects and screening plan online. You can also share your SHP with providers or family members. Having a digital copy of your SHP allows any new providers you may have to quickly get up to date on your medical history. Registered users can also browse resources on the site.

GRYT

https://grythealth.com/

GRYT is an award-winning, mobile app-based social community founded by cancer survivors and caregivers who wanted to create a more human approach to helping people live on their own terms.

Oncolink: Survivorship

https://www.oncolink.org/support/survivorship

OncoLink is a website maintained by the Abramson Cancer Center at the Hospital of the University of Pennsylvania. Their survivorship site features information and inspiration concerning the lifelong healthcare, emotional and social needs of cancer survivors.

Oncolink: Smart ALACC

https://smartalacc.oncolink.org/

The Smart Adult Living After Childhood Cancer (Smart ALACC) Care Plan is a "survivorship care plan" that provides cancer survivors with information regarding the health risks they face as a result of cancer therapies. Review and discuss the care plan with your healthcare team, so you can decide the best course of action to prevent and monitor any possible effects.

We Are More

https://wearemore.life/

Support network for patients and caregivers. Participate in stigma-free discussions, find like-minded people, get support, recommendations, enjoy exclusive member benefits and find yourself again.

Podcasts

AYA Cancer Chat: Life Interrupted

https://www.chop.edu/health-resources/aya-cancer-chat-life-interrupted

Listen in to a podcast where adolescents and young adults AYA from the Cancer Center at Children's Hospital of Philadelphia discuss their experiences with cancer diagnosis and treatment.

Life: With A Side of Cancer

https://cancerontheside.com/

Two young adults, Vinnie Cent and Sierra Missed, talk about LIFE, their experiences with cancer, and ways to elevate the young adult cancer community through conversation.

Improving Sleep

Sleep is an important part of health. Below are some websites and tips on how to improve your sleep and explaining why sleep is so important.

Information and Tips:
Many adolescents and young adults do not get enough sleep. The average amount of sleep they get is between 7 and 7.25 hours. However, studies show most adolescents and young adults need between 9 and 9.5 hours of sleep every night.

The following recommendations will help you get the best sleep possible and make it easier for you to fall asleep and stay asleep:

- **Sleep schedule**. Wake up and go to bed at about the same time on school nights and non-school nights. Bedtime and wake time should not differ from one day to the next by more than an hour or so.
- **Weekends**. Don't sleep in on weekends to catch up on sleep. This makes it more likely that you will have problems falling asleep at bedtime.
- **Naps**. If you are very sleepy during the day, nap for 30 to 45 minutes in the early afternoon. Don't nap too long or too late in the afternoon, or you may have difficulty falling asleep at bedtime.
- **Sunlight**. Spend time outside every day, especially in the morning. Exposure to sunlight or bright light helps keep your body's internal clock on track.
- **Exercise**. Exercise regularly. Exercising may help you fall asleep and sleep more deeply, but don't exercise too close (2-3 hours) to bedtime, as this can make it hard to fall asleep.
- **Bedroom**. Make sure your bedroom is comfortable, quiet and dark. Make sure that it's not too warm at night, as sleeping in a room warmer than 75°F will make it hard to sleep.
- **Bed**. Use your bed for sleeping only. Don't study, read or listen to music in your bed.
- **Bedtime**. Make the 30 to 60 minutes before bedtime a quiet or wind-down time. Relaxing activities done regularly, such as reading a book, listening to a calming play list, dimming the lights or drinking a cup of chamomile tea help your body and mind slow down and tell your body it's time for sleep. Don't watch TV, study or get involved in other "energizing" activities in the 30 minutes before bedtime.
- **To-do Lists**. If you find your mind races with to-do lists when you turn out the light, spend some time before you begin to wind down writing down your worries and to-do lists for the next day. If any thoughts pop into your head while trying to fall asleep, write them down and think about them the next day.
- **Electronics**. Turn off the TV, computer and cell phone before you begin your bedtime routine. Lights from these devices make your brain think it is daytime, making it harder for you to fall asleep.
- **Snack**. Eat regular meals and don't go to bed hungry. A light snack before bed is a good idea; eating a full meal in the hour before bed is not.
- **Caffeine**. Avoid eating or drinking products containing caffeine in the late afternoon and evening. These include caffeinated sodas, coffee, tea and chocolate.
- **Alcohol**. Ingestion of alcohol disrupts sleep and may cause you to awaken throughout the night.
- **Smoking**. Smoking disturbs sleep. Don't smoke for at least an hour before bedtime (and preferably, not at all).
- **Sleeping pills**. Don't use sleeping pills, melatonin or other over-the-counter sleep aids without talking to your healthcare provider first. These may be dangerous, and your sleep problems will likely return when you stop using the medicine.
- **Don't drive drowsy**. Teenagers are at the highest risk for falling asleep at the wheel, so don't drive when you haven't gotten enough sleep. Accidents are most likely to happen in the middle of the afternoon or at night.

Adapted from Mindell & Owens (2003). A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems. Philadelphia: Lippincott Williams & Wilkins.

National Sleep Foundation

https://www.sleepfoundation.org/sleep-topics

This interactive website provides information and tips from experts on how to improve sleep, myths vs. facts about sleep, and why sleep is important. Read or watch videos related to many sleep topics — including sleep and the adolescent brain.

Being Active

Following are some tips for becoming and/or staying physically active.

- **Do something you enjoy**. The best way to make sure you'll stay active is to find something you have fun doing. Shooting hoops, dancing, swimming, riding bikes, and walking in the park or mall are all great options.
- **Do something active with a friend**. Having a "workout buddy" that you don't want to let down and help keep you accountable is a great way to keep your exercise motivation up.
- **Put it in your schedule**. Try to plan out a time in your day to exercise. Setting aside a specific time of the day will help prevent you from putting it off until "later."
- **Be realistic** — everyone is built differently with varying athletic abilities. What may work well for others may not work well for you, and what may work for you may not work for others!
- **Remember to take time to rest** so you don't overwork your muscles.

Adapted from https://lombardi.georgetown.edu/patient/patient-family-resources/

Smoking Cessation

The following websites and resources provide information and support to individuals that want to quit smoking.

American Cancer Society

https://www.cancer.org/cancer/risk-prevention/tobacco.html

This website provides information and useful tips on quitting smoking.

Delaware Quitline

www.dhss.delaware.gov/dhss/dph/dpc/quitline.html

1-866-409-1858

The Delaware Quitline has specialists assess needs over the phone and connect callers with appropriate services — including phone or face-to-face counseling, follow-up support, information about quitting, a quit-smoking guidebook and vouchers to purchase stop-smoking aids. The Quitline is free and serves Delaware residents ages 13 and older.

New Jersey Quitline

www.njquitline.org/

1-866-NJSTOPS (1-866-657-8677)

The New Jersey Quitline offers free resources and telephone counseling for NJ residents. The website gives details on what to expect when you call, as well as information and resources on smoking cessation. Quit Coaches are available via phone weekdays 8 a.m. to 9 p.m., Saturday 8 a.m. to 7 p.m., Sunday 9 a.m. to 5 p.m. If you call after hours, you can leave a voicemail or listen to tips for quitting smoking.

Pennsylvania Free Quitline

https://pa.quitlogix.org

The PA Free Quitline is a free online service available to all Pennsylvanians. When you sign up, you get special tools, a support team of coaches, research-based information, and a community of others trying to become tobacco free. You can also speak to a coach by phone. They also offer a free supply of nicotine patches or gum.

Smoke-Free Philly

http://smokefreephilly.org

1-800-QUIT-NOW

Smoke-Free Philly matches you with a quit coach to help stop smoking. The website provides handouts and tools to help quit smoking.

BOOKS

General

Child Cancer: A Parent's Guide to Solid Tumor Cancers (2nd Edition)

By Honna Janes-Hodder & Nancy Keene

ISBN-13: 978-0596500146

This is a comprehensive guide to six solid-tumor childhood cancers: neuroblastoma, Wilms' tumor, liver tumors, soft tissue sarcomas, retinoblastoma and bone sarcomas. The chapters cover tumor origins, diagnosis, treatment, prognosis, clinical trials and therapy options. The authors are both mothers of children who had cancer and are patient advocates in the Children's Oncology Group. The book addresses emotional and psychological issues as well, with personal accounts to help parents and families cope with daily stress or end of life.

Childhood Cancer Survivors: A Practical Guide to Your Future (Childhood Cancer Guides)

By Nancy Keene, Wendy Hobbie & Kathy Ruccione

ISBN-10: 0596528515

Includes information on late medical effects of treatment, emotional aspects of surviving cancer, schedules for follow-up care, challenges in the healthcare system and lifestyle choices.

Childhood Cancer Survivorship: Improving Care and Quality of Life

By Maria Hewitt & Susan L. Weiner

ISBN-13: 9780309088985

This book outlines a policy agenda linking improved healthcare delivery, investments in education and training, and expanded research to an improvement in the long-term outlook for survivors of childhood cancer.

Childhood Leukemia: A Guide for Families, Friends and Caregivers (3rd Edition)

By Nancy Keene

ISBN-13: 978-0596500153

This parent guide covers not only detailed medical information about leukemia and the various treatment options, but also day-to-day practical advice on how to cope with procedures, hospitalization, family and friends, school, social and financial issues, communication, feelings, and, if therapy is not successful, the difficult issues of death and bereavement.

Mature Beyond Their Years: The Impact of Cancer on Adolescent Development

By Kathleen Neville

ISBN-13: 9781890504205

The book contains black-and-white illustrations and addresses the unique survivorship issues facing the adolescent with cancer.

Reimagine Well Learn Guide: Adolescent and Young Adult (AYA) Cancer: From Diagnosis to Wellbeing

By Martin Casella, Roger Holzberg, Adele Sender

ISBN-13: 978-0999236437

If you or someone you love has been diagnosed with cancer and you are between the ages of 15 and 39, this Adolescent and Young Adult (AYA) Learn Guide will help you through the anxiety of a cancer diagnosis.

Riding the Cancer Coaster: Survival Guide for Teens and Young Adults

By Clarissa E. Schilstra

ISBN-13: 978-1514208083

Through her own experiences as a two-time cancer survivor, and previous teen cancer patient who faced a forty percent chance of survival, Clarissa Schilstra has learned a great deal about all of these challenges and how to cope with them.

The C-Word: Teenagers and their Families Living with Cancer

By Elena Dorfman

ISBN-13: 978-0939165216

In this book, five teens with cancer, their families and best friends are interviewed about the effects the disease has had on their lives.

THRIVE/SURVIVE e-book

https://triagecancer.org/wp-content/uploads/2017/03/10toThrive2017.pdf

As a young adult, there is a lot of focus on fighting cancer and treating cancer, but what about life on the other side of survivorship? That's where 10 to Thrive comes in — an easy-to-navigate e-book of top 10 lists dealing with 10 different areas of a young adult survivor's life, such as career, finance and dating. The content in the e-book is supplied by experts, leaders and organizations in the cancer community.

Walking with a Shadow: Surviving Childhood Leukemia

By Nanci A. Sullivan

ISBN-13: 9780275958145

In this guide for teachers, counselors and other professionals working with children with leukemia, Sullivan offers recommendations for lessening the effect of isolation and learning disabilities. The book also provides a list of resources, a glossary of common cancer terms and an explanation of blood tests.

Zen Teen: 40 Ways to Stay Calm When Life Gets Stressful

By Tanya Carroll Richardson

A warm and relatable teen guide to reducing anxiety, depression and panic while developing resilience and confidence with 40 tips and tricks that guide, support and inspire teens to keep calm and stay mindful.

Academic/Learning-focused Resources

Educating the Child with Cancer: A Guide for Parents and Teachers

By Ruth Hoffman

ISBN-13: 978-0972404334

This resource provides a wealth of knowledge about the special problems children who have or have had cancer exhibit within educational contexts. Strategies for teaching and learning are discussed in detail.

K&W Guide to College for Students with Learning Disabilities (14th Edition)

By Princeton Review

ISBN-13: 978-0375764950

Finding the perfect college for a student with a learning disability can be a frustrating and time-consuming process. This resource includes more than 300 school profiles, and the following information:

- Strategies for finding the right program
- Services available at each college — from tutors to special testing arrangements
- Admissions requirements for each program
- Policies and procedures about course waivers and substitutions
- Contact information for program administrators
- Advice from specialists in the field of learning disabilities
- Quick Contact Reference List with essential program information for an additional 1,000 schools

Self-Advocacy Skills for Students with Learning Disabilities: Making It Happen in College and Beyond

By Henry Reiff

ISBN-13: 978-1934032060

Filled with strategies and resources, this book uses the author's groundbreaking research about successful adults with learning disabilities to teach survivors how to advocate for their needs. It is easily understood by students with learning disabilities, their parents, guidance counselors and other important individuals in the fields of both higher education and special education.

Children's Hospital of Philadelphia®

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Every day, teams at Children's Hospital of Philadelphia make breakthroughs that transform children's lives. Since our founding in 1855 as the nation's first children's hospital, we have made extraordinary discoveries, trained generations of leaders, and advocated for children everywhere. Our pediatric research program, one of the largest in the country, has set a new standard for scientific innovation around the world. As a nonprofit charitable organization, we rely on the generous support of donors who are inspired by our work — and our mission.