Resource Guide for Adolescent and Young Adult Survivors of Cancer

The Children’s Hospital of Philadelphia®

cancer.chop.edu
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Welcome

This Resource Guide has been compiled to identify important resources that may be helpful to adolescent and young adult (AYA) survivors of cancer. The ability to access information quickly and efficiently is important when confronting specific concerns and planning for the future. Readers are encouraged to explore and use the services listed in this resource guide, which all exist to support survivors with financial, employment, emotional, social, and health needs/concerns. The sections of this manual are divided by topic and organized alphabetically in order to make it easy to find each resource. Given the huge amount of resources available nationwide, there are more services available to you than listed in this guide. Instead, we focused on including the many resources available in the tri-state (PA, NJ, DE) area. 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.
Transition to Adulthood: School, Employment, and Daily Life Resources and Accommodations

Legal Responsibilities of the School

Schools are required by law to provide support and accommodations for students with physical and cognitive impairments.

The Rehabilitation Act of 1973 (Public Law 93-112): Section 504


This law requires all programs and activities that receive federal funding (for example, public high schools, public universities, government jobs) to accommodate individuals with physical or cognitive impairment(s). Examples include that public schools must make appropriate accommodations for students who use wheelchairs, and employees with disabilities must be given access to assistive technology if needed.

The Education for All Handicapped Children Act of 1975 (EHA; Public Law 94-142)

This law requires every child with a qualifying disability to be educated in the least restrictive environment. In most cases, each child with an illness or disability must have a written individualized education plan (IEP), which outlines the services necessary for the child. Parents have rights to due process with recourse for grievances through the state educational system or civil courts.

Individuals with Disabilities Education Improvement Act of 2004 (IDEA)

http://idea.ed.gov

This law broadened services available to students with a chronic illness, including assistive technology services as part of an IEP, and transition services for adolescents.


Individualized Education Plan (IEP) and 504 Plan

What is an IEP?

An Individualized Education Plan (IEP) is a legal document that describes exactly what special education services the student will receive to assist with learning and the rationale behind these services.

What is a 504 Plan?

A 504 Plan refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. A 504 plan is a legal document that describes accommodations needed for the student to have an opportunity to perform at the same level as peers.

- Both provide specialized instruction; however, a 504 plan does not involve federal funding.
- The type of plan that the student requires is based on the individual learner and his/her needs.
<table>
<thead>
<tr>
<th>What’s the difference between an IEP and a 504 plan?</th>
<th>IEP</th>
<th>504 Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who is eligible?</strong></td>
<td>A student in kindergarten through 12th grade who has a disability which requires specialized education.</td>
<td>A student from kindergarten through college who has a physical, mental, or other health impairment that interferes with major life activities, but can learn from the regular education curriculum.</td>
</tr>
<tr>
<td><strong>What type of accommodations can be provided?</strong></td>
<td>Special education program that is entirely different from the learning plans that non-IEP students are using. For example, a special educator may use a different method for teaching math. In addition, related services can be provided, such as transportation, speech therapy, physical therapy, occupational therapy, psychological counseling, and assistive technology.</td>
<td>The student learns from the regular curriculum but has accommodations such as untimed tests, extra time to finish written assignments, or a recording device for class.</td>
</tr>
<tr>
<td><strong>What is the process for obtaining an IEP or 504 plan?</strong></td>
<td>School personnel may suggest a multi-disciplinary team evaluation or a parent may request the same in a letter to the school principal. The team evaluates the student’s health and learning style to identify needs or disabilities. If the family obtains a private evaluation, the school district can consider the findings, but is not required to do so.</td>
<td>Parent writes a letter to the school principal explaining the student’s diagnosis and type of accommodations the student needs. The parents can give the district private evaluations that explain the child’s condition and needs, or the school can conduct its own evaluation.</td>
</tr>
<tr>
<td><strong>Can the plan ever be changed?</strong></td>
<td>Yes, the team is required to monitor the student and adjust the plan as necessary and annually. Parents may request an IEP meeting at any time to review or suggest changes.</td>
<td>Yes, the team monitors the student and will adjust the plan as necessary and annually. Parents may request a review meeting at any time.</td>
</tr>
<tr>
<td><strong>What about college students?</strong></td>
<td>IEPs do not exist in the post-secondary/college setting.</td>
<td>All documentation must be provided by the student (colleges will not test for learning disabilities/impairments). The 504 plan will outline accommodations for the survivor, such as extended time for tests, priority registration, help with note taking, or a TTY for a student with hearing impairment. Check with your college’s disability office for more information.</td>
</tr>
</tbody>
</table>

*Information obtained from the Education Law Center’s brochure, “A Comparison of the Rights of a Child with a Disability Who Needs ‘Special Education’ and a Child Who is a ‘Protected Handicapped Student’.”*
Sample IEP Accommodations

Environmental Accommodations:
- Assign school staff to check in with the student regularly
- Provide preferred seating as necessary to assist with focusing and maintaining attention
- Provide instructions both in writing and verbally
- Provide appropriate assistive technology
- Provide a private area in which to rest
- Shorten the child’s school day or limit the number of classes

Organizational Accommodations:
- Provide review/reinforcement opportunities for new concepts
- Provide extra time to complete assignments
- Break large tasks down into smaller parts

Accommodations to Facilitate Memory:
- Include experiential learning, play-acting, or humor activities in learning plan.
- Teach mnemonic memorization strategies
- Provide multiple opportunities to learning in new ways

Reading Accommodations:
- Provide instructional materials geared towards student’s instructional level (for example, high interest, low vocabulary reading material)
- Allow students to use a highlighter when reading in order to help better understand the material

Written Language Accommodations:
- Allow use of a computer for word processing, proofreading, editing
- Adjust the required length and appropriate deadlines for written assignments

Testing Accommodations:
- Allow additional time
- Provide a quiet location which is free from distraction
- Allow flexibility in the number of questions to be answered

Emotional/Social Accommodations:
- Provide individual school counseling or social skills group
- Provide awareness training to appropriate staff/students
- Begin friendship groups for the student; establish peer support

Sample 504 Plan Accommodations

504 accommodations for survivors can vary widely depending on the type of cancer. Some physical accommodations in the classroom may no longer be needed after a patient’s treatment ends. In addition, if the school decides the 504 plan is no longer needed and the patient is not eligible for an IEP, a parent or social worker can suggest a yearly meeting and a letter in the child’s school record detailing risk for possible future cognitive effects of treatment, such as difficulty with concentration, memory or processing speed, that may warrant implementation of a 504 plan or IEP in the future. Check with your physician for specific learning deficits that may be related to specific types of chemotherapy and radiation.

Classroom/Environmental Accommodations:
- Preferred seating
- Water bottle or snacks on desk
- Elevator access

Organizational Accommodations:
- Provide extra time to complete assignments

Reading Accommodations:
- Allow students to use a highlighter when reading in order to help better understand the material

Written Language Accommodations:
- Allow use of a computer for word processing, proofreading, editing

Testing Accommodations:
- Additional time on tests
- Provide a quiet location which is free from distraction
Additional Resources for Assistance

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

Education Law Center (ELC)
www.elc-pa.org
1315 Walnut Street, 4th Floor, Philadelphia, PA 19107
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.

Federation for Children with Special Needs
www.fcsn.org
A federally funded organization providing information on special education rights and laws, conferences, referrals for services, parent training workshops, publications, and advocacy information.

National Center for Learning Disabilities
www.ncld.org
381 Park Avenue South, Ste 1401, New York, NY 10016
1-888-575-7373
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 access to the internet. The website has a searchable database that helps locate nearby resources related to education through ZIP code.

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 Post-High School Education and Training

Individualized Transition Plans (ITPs)

Transition planning should begin in the early years of middle school, when students are beginning to gain work skills and credits toward high school graduation. Special education students have a right to be prepared for graduation, higher education, and work in ways that fit their needs. For some survivors, extra support will be needed to smooth the transition from high school to adulthood.

Transition plans should include:

- Desired post-school outcomes (for example, work, college)
- Necessary documents and support services
- List of transition resource team
- Career preparation activities
- Transition services for instruction, community experiences, employment, post-school living, and daily living skills
- Vocational evaluation
- Summary of agency responsibilities
- Summary of designated instruction and services for transition

What transition services are available for high school students with learning disabilities (LD) and an IEP?

At the high school level, transition services for students who have LD and an IEP are available through their special education programs and general education programs.

Special education staff provides assistance with the following:

- Counseling
- Identifying employment interests
- Education and employment planning
- Goal setting
- Pre-employment skills training
- Academic support
- Links to specific programs and services

Other transition-related services that are available to all high school students include:

- Guidance counseling
- Career center services
- Work experience education
- Academy programs
- Career education and employment courses

Check with your school’s special education teacher and/or your school district’s office of student personnel services to see which specific programs are offered.

What are some important things to consider and do when creating a transition plan during high school?

- The plan should be individualized and person-centered.
- Tell the transition coordinator about your interests and abilities to help them recommend and/or help set up work experiences.
- Ask what you will do at the work site.
- Ask for letters of reference from your supervisors or teachers.
- Create your resume, including volunteer experience, school and extra-curricular activities, honors, etc.
- If you or your family feels uncomfortable with the transition plan, call a team meeting to discuss the issues.
- During the last year of high school, work with the transition coordinator to select an adult provider agency to help after graduation.
College for Survivors with Disabilities

What about services/accommodations for college admissions tests?

High school students who are considering college should begin to consider special accommodations for tests (for example, PSAT and SAT) as early as ninth grade. Despite solid academic performance, survivors of cancer may experience difficulty on the timed nature and long duration of standardized achievement tests, especially considering potential late cognitive effects. It is important for students and their parents to raise these concerns with the guidance counselor and school psychologist so that services can be provided, as these tests often determine admission and financial aid at higher educational institutions. A number of colleges also offer the option to not take admissions tests. In addition, when a student begins college, it is easier to begin the process of accessing services at college institutions if the student has prior testing and documentation of difficulties from high school.

What are some tips for researching and planning for college?

- Ask the guidance counselor or IEP team whether local colleges offer non-credit peer-assisted programs for high school students.
- If you have an IEP, ask to include goals for after high school in the Transition IEP.
- Obtain current documentation of your late effects or disability from your doctor.
- Meet with staff from the college’s Disability Service Office to discuss plans, goals, and accommodations.
- Explore transportation to and from campus.
- Ask about financial aid resources and funding for an educational coach to attend class with you, if needed.
- Inquire about Social Security’s PASS Program (Plan to Achieve Self-Support) if you receive SSI.
- Universities communicate directly with students, not with parents. Consider signing a release so that your parent(s) are included in your communication with the universities/colleges.

Source: www.thinkcollege.net

What should I consider when selecting and applying to college?

Survivors with cognitive late effects (learning problems) may need some help applying for and attending college. These survivors should evaluate colleges carefully and apply to those which will best address their special needs. Survivors with physical challenges should carefully plan class times to make sure there is enough time to travel between buildings.

When visiting colleges, set up appointments at the disability services office to share information about your needs and find out how the college can accommodate them. All colleges offer students with learning disabilities special help (untimed tests, tutoring, and note takers), and some colleges also offer special studies majors (designed around the student’s strengths), a lighter class load, or waivers from course requirements.

While other admission criteria generally must be met, it is against the law to deny admission to students based on disabilities. Public universities and community colleges may waive some admission criteria for disabled students on a case-by-case basis if the student can show that she is capable of college-level work. For example, if a student’s poor hand/eye coordination made getting a high score on the SAT difficult, but the student will have a classroom aide available at college to make up for this problem in class, they might be admitted despite the low score. Standardized test requirements might also be set aside if high school grades or the student’s work portfolio are strong and a number of universities now offer “no test” admissions review.

Schools that normally require all freshmen to live on campus may waive this requirement for a student with special needs. If living at home is not an option, a group home or supervised apartment near campus might be. Be sure you have secured safe and appropriate housing, found competent local professionals to provide ongoing care, and rehearsed daily life activities like grocery shopping and visiting the laundromat, if necessary. You may want to work out a plan with your parents, just in case a problem arises.

Accommodations for Students with Disabilities in College

If you have a disability for which you may be requesting accommodations, contact the Office of Academic Support Services at the college. You will need documentation from this office before accommodations can be granted. Other programs that may be helpful to you that are typically found at colleges or universities include a Tutoring and Studying Center and, as already mentioned, an Office of Disability Services.

When applying to a higher educational institution, students requesting disability services should be prepared to present documentation that shows eligibility for services and specific accommodations as soon as possible. Check with each college/university for specific requirements of this documentation of eligibility. For example, documentation should:

- Be prepared by a qualified professional in the appropriate field of concern (for example, a doctor or therapist), who is not a family member of the student.
- Be typed, signed and on official letterhead.
- Include an identified diagnosis.
- Describe the student’s current academic, emotional, and/or health function, as appropriate.
- Describe any functional limitations.
- Include suggested educational recommendations and the assessments.
- Include all important information about educational and health histories. Include the names and scores of testing assessments used to make specific determinations.

Scholarships for Pediatric Cancer Survivors

If you need financial support to pursue your college degree, there are scholarships available to survivors of pediatric cancer. Visit CHOP’s Cancer Survivorship Program website to view a list of scholarship opportunities.

Source: http://www.chop.edu/service/transition-to-adulthood/transition-programs
267-426-5569
REACH@email.chop.edu

REACH for College is a two-session workshop at CHOP for students ages 15 to 19 with chronic illness and their parents. The sessions focus on the medical and social transitions necessary to plan for and navigate college life successfully. With the help of college-aged mentors attending college with chronic illness, CHOP physicians and social workers, as well as representatives from the Office of Disability Services at a local college, participants and their parents are able to work towards a successful transition to college.

Transition to Adulthood Resources

Becoming an adult brings opportunities to be more independent, have a job, and/or further one’s education. The following resources provide support for adolescents and young adults with special healthcare needs and disabilities to help them make a successful transition into adulthood — whether that means helping them find a job, keep their job, get into college, get involved in their community, and/or become more self-sufficient in other areas of their lives.

Cancer and Careers

Provides resources for returning to work after cancer treatment, including tips on writing a resume, job hunting, and making an effective profile on LinkedIn.

Center for Independent Living

This program supports independent living for individuals with disabilities so individuals can expand their options and maintain more self-sufficient and productive lives in the community.
Jewish Employment and Vocational Services (JEVS)

www.jevs.org
A.P. Orleans Center, 1330 Rhawn Street,
Philadelphia, PA 19111
215-728-4436

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)

www.jan.wvu.edu
PO Box 6080, Morgantown, WV 26506
800-526-7234
jan@jan.wvu.edu

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.

New Jersey Division of Vocational Rehabilitation Services (NJ DVRS)

lwd.dol.state.nj.us/labor/dvrs/DVRIndex.html
P.O. Box 398, 135 East State Street, Trenton, NJ 08625
609-292-5987

The New Jersey Division of Vocational Rehabilitation Services (DVRS) provides services that enable individuals with disabilities to find jobs or keep their existing jobs.

Office of Vocational Rehabilitation (OVR)

www.portal.state.pa.us/portal/server.pt/community/vocational_rehabilitation/10356
444 North Third Street, 5th Floor, Philadelphia, PA 19123
800-442-6352 (Pennsylvania) or 215-560-3117
(Philadelphia Office)

The OVR’s mission is to help Pennsylvanians with disabilities to 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.

REACH

www.chop.edu/service/transition-to-adulthood/transition-programs
267-426-5569
REACH@email.chop.edu

REACH (Rapport, Empowerment, Advocacy, through Connections and Health) is a program for teens and young adults ages 14-22 with special healthcare needs and their families, created by teens and young adults with special healthcare needs at CHOP. REACH’s mission is to prepare teens and young adults with special healthcare needs for a successful transition into adulthood by providing peer support, guidance and resources. REACH offers mentorship and training to help youth acquire the skills needed to develop and maintain partnerships among families, youth and providers as they move through transition.

Transition to Adulthood Resource Manual

Jennifer Plumb, M.S.W., and Symme Trachtenberg, M.S.W.
The Children’s Hospital of Philadelphia

The resource manual provides information on self-advocacy, laws related to adolescent transition, a transition checklist and timeline, and areas for transition planning in a user-friendly format. It also provides information regarding healthcare, education, employment, and recreation. Each area contains a checklist, planning sheet, and links to helpful local and national resources. An annotated Individualized Education Program (IEP) is also provided.
Financial, Transportation and Legal Resources for Survivors

National Financial Resources

The following organizations provide information and support to survivors in need of financial assistance related to employment issues, need for alternative treatment for late effects, health insurance issues, medication expenses, and other financial needs.

Leukemia & Lymphoma Society: Financial Health Matters

www.lls.org/content/nationalcontent/resourcecenter/freeducationmaterials/generalcancer/pdf/financialhealthmatters.pdf

This online booklet describes health insurance options and resources to help patients and their families cope with the financial aspects of cancer care. It may be helpful to skim through the entire booklet, and then come back to specific sections as needed.

LIVESTRONG: Practical Effects of Cancer


This website provides links to information on assistance programs, employment policies, financial management, insurance, and healthcare planning.

Lucy’s Love Bus: Integrative Therapies Project

www.lucyslovebus.org
978-834-6490

This organization will give up to $1,000 to survivors up to 21 years old to receive alternative therapies to help cope with late effects from cancer or treatment. Examples of alternative therapies are acupuncture, massage, horseback riding, meditation, art, music, tai chi, and dance therapy.

Partnership for Prescription Assistance

www.pparx.org
888-477-2669

This website brings together drug companies, doctors, other healthcare providers, patient advocacy organizations and community groups to help patients who lack prescription coverage get the medicines they need.

Patient Advocate Foundation (PAF)

www.patientadvocate.org
1-800-532-5274
help@patientadvocate.org

The Patient Advocate Foundation (PAF) is a national non-profit organization that provides education, legal counseling, and referrals to cancer patients and survivors about healthcare, insurance, financial issues, job discrimination, and debt crisis matters. The PAF's Co-Pay Relief Program provides limited payment assistance for medicine to insured patients who financially and medically qualify. For more information about the Co-Pay Relief Program, visit www.copays.org or call 1-866-512-3861.

Surviving and Moving Forward: the SAMFund for Young Adult Survivors of Cancer

www.thesamfund.org
866-439-9365
info@thesamfund.org

The SAMFund is a non-profit organization created to help young adult survivors (ages 17-30) of cancer with a successful transition into their post-treatment life, by providing financial support through grants and scholarships. In order to be eligible for the grants, you must be a young adult between the ages of 17 and 35, be finished with active cancer treatment, and be a resident of the United States. The application process begins in June of each year.
Sy's Fund
sysfund.org
413-512-9177
sysfund@gmail.com

Sy's Fund helps young adult survivors with severe ongoing medical issues related to cancer or its treatment by providing them with gifts or money to pursue hobbies or creative passions, as well as alternative therapies like acupuncture and therapeutic massage.

Financial Resources for New Jersey Residents

If you and your family live in New Jersey and need financial assistance for cancer-related medical bills, check out these resources.

Catastrophic Illness in Children Relief Fund Program
www.nj.gov/humanservices/cicrf/home/index.html

A catastrophic illness is any illness or condition, acute or chronic, where expenses are not fully covered by insurance, state, federal programs, or other sources and exceed the program’s eligibility threshold. In order to be eligible, the child must have been 21 years or younger when the medical expenses occurred; have residence in New Jersey for 3 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
800-701-0710

Available to families who have been denied by the SSI Program. 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.

Checklist of what you need to apply: www.nj.gov/humanservices/dmahs/clients/medicaid/medically_needy_checklist.pdf

Transportation Assistance

If you need assistance with regular or one-time transportation, check out the following resources or talk to your social worker.

Logisticare Medical Transportation (New Jersey)
www.state.nj.us/humanservices/dmahs/home/logisticare.html
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 2 days before you need the ride.

Medical Assistance Transportation Program (Pennsylvania)
matp.pa.gov

Phone number specific to your county: matp.pa.gov/CountyContact.aspx

The Medical Assistance Transportation Program (MATP) is a transportation service available to people receiving Medical Assistance and is paid for by the Pennsylvania Department of Public Welfare (DPW). The program will provide paratransit to people with disabilities, mileage reimbursement or public transportation. Each county has its own provider company, so be sure to call your county’s provider well ahead of your appointment date to register and sign up for a ride.

Philly Patient Ride
www.patientride.org/how-it-works/overview/

Volunteers pick up patients at their home in a PhillyCarShare vehicle and drive them to their cancer-related appointment at HUP, Hahnemann, Pennsylvania Hospital, Jefferson/Kimmel, and Temple (not CHOP), and then drive them home after the appointment. If you are interested, talk to your social worker.
Road to Recovery

www.cancer.org/treatment/supportprogramsservices/road-to-recovery
1-800-227-2345

The American Cancer Society’s Road to Recovery Program matches volunteer drivers with patients who need rides to cancer-related appointments. This service is available nationwide, but 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.

Online Legal Information

These organizations assist survivors and individuals with disabilities to learn about and advocate for their legal rights.

Cancer Legal Resource Center (CLRC)

www.disabilityrightslegalcenter.org/cancer-rights-program
(866) 843-2572 (Monday-Friday, 12pm – 8pm EST)
CLRC@LLS.edu

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

Childhood Cancer Ombudsman Program

The Childhood Cancer Ombudsman Program provides complaint investigation and resolution for families of children with cancer and adult survivors of childhood cancer. They provide information and research options to families so that they may better exercise their rights in decisions in the areas of medical treatment, schooling, rehabilitation, employment, and insurance reimbursement/coverage. They work with and refer to local cooperating attorneys in some cities, as well as numerous other organizations to provide medical record reviews and answer specific questions about treatment options and alternatives.

Disabilities Rights Network of Pennsylvania

www.drnpa.org
The Philadelphia Building, 1315 Walnut St., Suite 400, Philadelphia, PA 19107 (215) 238-8070
Text/TTD: (215) 789-2498
drnpa-philad@drnpa.org

The mission of the Disability Rights Network of Pennsylvania is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities. Provide publications related to access, assistive technology, education, employment, estate planning/guardianship, housing, medical, mental health advance directives, mental health, and parking. Links to online resources are also available.

Law Resources for Individuals with Disabilities

1-88-88-disabled.com
1-88-88-DISABLED
disabled@1-88-88-disabled.com.

1-88-88-DISABLED is dedicated to helping deserving individuals get through all regulations in becoming a SSD (Social Security Disability) or SSI (Social Security Income) recipient. This national system of lawyers aids people with disabilities taking the steps to receive federal benefits.

Legal Handbook for Cancer Survivors

This handbook discusses ways to pay for medical care, how to work through financial and employment issues, and recommends additional resources. It is written for the Washington, D.C. area, but it also discusses national laws and budgeting strategies. A PDF of the book is available free at www.vsb.org/docs/conferences/young-lawyers/cancersurvivorshandbook.pdf.

National Cancer Legal Services Network

www.NCLSN.org

The 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.
US Department of Justice ADA Information Line, Civil Rights Division:
www.ada.gov/infoline.htm
800-514-0301
Provides information related to the Americans with Disabilities Act (ADA). Explains the process of filing a complaint and resolving disputes.

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; 42 U.S.C. 12101 et seq.)
www.ada.gov
- 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.

Family and Medical Leave Act (FMLA; 29 U.S.C. 2601 et seq.)
www.dol.gov/whd/regs/statutes/fmla.htm
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 disrupt unduly 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 and 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.

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

Insurance Information for Survivors

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

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

Health Insurance Portability and Accountability Act (HIPAA)
www.hhs.gov/ocr/privacy/index.html
HIPAA helps cancer survivors retain their health insurance by:
- 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.

- Prevents group health plans from denying coverage based on health status factors such as medical history and genetic information.

www.dol.gov/dol/topic/health-plans/cobra.htm

- 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.

- Although the survivor must pay for the continued coverage, the rate may not exceed by more than 2 percent the rate set for the survivor’s former co-workers.

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

- 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.

**The Affordable Care Act (2010)**
www.healthcare.gov/law/index.html
www.healthcare.gov/what-is-the-marketplace-in-my-state

- 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.


**Federal Health Insurance and Disability Programs**
The following health insurance programs are funded by the federal government.

**Medicaid and State Children’s Health Insurance Program (S-CHIP)**
www.medicaid.gov

Medicaid is joint federal/state insurance for low income and disabled individuals.

Covers approximately 36 million individuals including children, the blind, the disabled, and people who are eligible to receive federally assisted income maintenance payments. Rules on eligibility for Medicaid vary from state to state. Medicaid sometimes pays transportation and prescription costs.

**Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT)**
www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html

This benefit provides comprehensive and preventive healthcare services for individuals under age 21 enrolled in Medicaid, including appropriate diagnostic, screening, preventive, rehabilitative, dental, mental health, developmental, and specialty services.

**Supplemental Security Income (SSI)**
www.ssa.gov
Philadelphia Region: www.ssa.gov/phia
New York Region: www.ssa.gov/ny

Federally funded program that provides monthly payments to the elderly, blind, and children and adults with disabilities. Eligibility depends on your family income. Apply at your local Social Security Administration office or call 1-800-SSA-1213. For free help with both SSI and Medicaid,
FAX the Childhood Cancer Ombudsman Program at (804) 580-2502 or (804) 580-2304.

**Medicare Disability Program**

[www.ssa.gov/pubs/10043.html](http://www.ssa.gov/pubs/10043.html)

Medicare eligibility 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.


**Online Health Insurance Information**

Some survivors may qualify for health insurance programs that are funded by their state or other sources.

**Guaranteed Issue Health Insurance**

[www.guaranteed-issue-health-insurance.com/existing/health-insurance-cancer-survivor.htm](http://www.guaranteed-issue-health-insurance.com/existing/health-insurance-cancer-survivor.htm)

Website offers health insurance for cancer survivors.

**HealthCare.gov**


Learn about insurance options and the Affordable Care Act through this website managed by the U.S. Department of Health and Human Services.

**Healthcare Marketplace**


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

**Medical Assistance in Pennsylvania**

[www.dpw.state.pa.us/foradults/healthcaremedicalassistance/index.htm](http://www.dpw.state.pa.us/foradults/healthcaremedicalassistance/index.htm)

This is a state program that helps families who qualify pay for medical expenses. Due to a provision in the laws regarding Medical Assistance, children 18 and younger with serious disabilities who live in Pennsylvania are eligible for Medical Assistance (also known as Medicaid) regardless of their parents’ income. Thus, those children whose parents’ income is too high for SSI can qualify for Medicaid under this provision. For children who are already insured, Medicaid becomes a secondary policy that will cover expenses that are not covered by the first. To apply, contact your local Department of Public Assistance (DPA) office or visit our Department of Family Health Coverage Programs.

**National Coalition for Cancer Survivorship**


Provides a publication entitled, “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.

**Pennsylvania Health Law Project**

[www.phlp.org](http://www.phlp.org)

1-800-274-3258
TTY: 1-866-236-6310
staff@phlp.org

The Pennsylvania Health Law Project helpline is available Monday through Friday from 9 a.m. to 5 p.m. to provide free information, advice, and direct representation to persons 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

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.

Bone Marrow and Stem Cell Transplant Survivor Support Group
Kimmel Cancer Center at Thomas Jefferson University Hospital
111 S. 11th St., Philadelphia, PA 19107
Phone: 215-503-7711
Bone Marrow Transplant Survivors Support Group is a monthly support group for individuals who have experienced a bone marrow transplant and their support persons. Free of charge.

Breast Cancer Survivors Network
Riddle Hospital Administrative Annex Conference Room
1068 West Baltimore Pike, Media, PA 19063
Contact: Deb Mantegna 610-891-3560
The “Breast Cancer Survivors Network” is open to women diagnosed with or who have a history of breast cancer. Attendance of family members is welcomed. No registration is required.

CancerCare of New Jersey
www.cancercare.org/about_us/contact_us/new_jersey.php
141 Dayton Street, Ridgewood, NJ 07450
201-444-6630 or 1-800-813-HOPE (4673)
njinfo@cancercare.org
CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs — including counseling, education, and practical help — are provided by trained oncology social workers and are completely free of charge. Satellite offices exist in Millburn, Princeton, Trenton, and Somerville, NJ.

Cancer Support Community/Gilda’s Club
The Cancer Support Community and Gilda’s Club provides resources and social and emotional support for those who have cancer or have survived cancer. Services are completely free of charge, include support groups, stress management, education programs, nutrition workshops and social events. They also have an extensive program for children and teens.
Find a local affiliate: www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-Program

Cancer Support Community of Greater Lehigh Valley
www.cancersupporttglv.org
3400 Bath Pike Bethlehem, PA 181017
610-861-7555

Cancer Support Community of Greater Philadelphia
www.cancersupportphiladelphia.org/
4100 Chamounix Drive, West Fairmount Park, Philadelphia, PA 19131
215-879-7733

Our Clubhouse
(formerly Gilda’s Club of Western Pennsylvania)
www.ourclubhouse.org/
2816 Smallman Street, Pittsburgh, PA 15222
412-338-1919

Gilda’s Club of Northern New Jersey
www.gildasclubnnj.org/
575 Main Street, Hackensack, NJ 07601
201-457-1670
info@gildasclubnnj.com

Gilda’s Club South Jersey
www.gildasclubsouthjersey.org/
700 New Road, Linwood, NJ 08221
609-926-2699
info@gildasclubsouthjersey.org

Ocean of Love
www.ocean-of-love.org
1709 Hwy 37E
Toms River, New Jersey 08753
732-270-3500
Ocean of Love is an organization serving children with cancer and their families who live in Ocean County, NJ. They have a monthly group for older teens and young adults that includes survivors and on treatment patients.
CHOP AYA Cancer Center Facebook Group
www.facebook.com/groups/CHOPAYA/

The CHOP AYA Facebook group is a group of current and former adolescent and young adult (AYA) CHOP patients. The Facebook group exists to establish connections between AYA treated for cancer and increase awareness of resources available for AYA. Go to the link above and join the group to learn more!

Navigating the New Normal
www4.kimmelcancercenter.org/kcc/clinical/patients/support-programs/navnewnormal/index.html

A program through the Kimmel Cancer Center at Thomas Jefferson University, in partnership with the Lance Armstrong Foundation, that provides support and education for young adults in the Philadelphia region who are living with cancer or a history of cancer.

Walkabout: Looking In, Looking Out

Walkabout uses a combination of techniques designed to decrease distress associated with illness, including pain, depression, and fatigue. Each session includes a check-in, meditation, mindful walking and yoga, photography, collage-making, and group dialogue. The program is free. All cancer fighters and survivors aged 18-30 are eligible to attend the eight-session program.

Young Survival Coalition
www.youngsurvival.org/

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 healthcare, as well as support and advocacy programs.
National Groups and Organizations

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

**American Association for Cancer Research (AACR)**


615 Chestnut St. 17th Floor, Philadelphia, PA 19106

The Survivor and Patient Advocacy Program creates mutually beneficial and enduring partnerships among cancer survivors, patient advocates, and scientific communities. Membership applications are available for cancer survivors who wish to become survivor advocates.

**American Cancer Society: Cancer Survivors Network (CSN)**

[csn.cancer.org](http://csn.cancer.org)

Provides information for survivors related to being healthy after treatment, ongoing research, and local resources for help. The goal is to create a community of cancer survivors and families through online chats and message boards, the Cancer Survivors Network, and support groups.

**American Cancer Society: National Cancer Information Center**

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**

[www.acco.org](http://www.acco.org)

1-800-366-CCCF

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.

**Association of Pediatric Oncology Social Workers (APOSW)**


The Association of Pediatric Oncology Social Workers provides resources regarding what to expect at the end of treatment and beyond. Information includes cognitive late-effects and emotional issues after cancer. The APOSW seeks to connect survivors with social workers if the survivor needs additional supportive services to help cope with the time after cancer treatment.

**Bite Me Cancer**

[www.bitemecancer.org/](http://www.bitemecancer.org/)

Bite Me Cancer is an organization that was started by a 19-year old with thyroid cancer. The group conducts fundraisers and has a teen discussion group on Facebook (no adults allowed).

**BMT InfoNet's Caring Connections Program**

[www.bmtinfonet.org/services/support](http://www.bmtinfonet.org/services/support)

This program matches bone marrow transplant patients and caregivers with survivors and experienced caregivers. Sign up online.

**Camp Mak-A-Dream Young Adult Survivors Conference (YASC)**

[www.campdream.org](http://www.campdream.org)

406-549-5987

YASC is a six-day, cost-free, medically supervised educational program in Montana designed to address issues of survivorship, provide information about being a cancer survivor, and develop lasting supportive relationships between young adult survivors. They also offer The Head's Up Conference, designed specifically for young adult survivors of brain tumors. The conferences offer workshops, professional talks, small group discussions with other participants, and recreational activities like hiking, swimming, working in an art studio, and soaking in the hot tub.

**Cancer.net**

[www.cancer.net/patient/Survivorship](http://www.cancer.net/patient/Survivorship)

Cancer.net has resources and discussions focusing on survivorship, steps to take after cancer, information about late effects, and rehabilitation. Survivors share stories on the message board.
CancerClimber Association (CCA)
www.cancerclimber.org
This organization was started by Sean Swarner, who survived two different forms of cancer at the ages of 13 and 16. He was the first cancer survivor to climb to the top of Mount Everest — the highest peak in the world. 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.

CancerEducation.com
www.cancereducation.com/cancersyspagesnb/a/lls/lls0201/index.cfm?rid=29
The Leukemia & Lymphoma Society and the National Coalition for Cancer Survivorship have developed an education program for cancer patients, family, caregivers, and health professionals called Cancer: Keys to Survivorship. This audio program provides the information for cancer survivors to advocate for themselves, including information about health insurance, Social Security, and disability programs.

Cancer Information and Counseling Line (CICL)
www.amc.org/cancer-resources
1-800-525-3777 (Monday-Friday, 10:30am to 6:30pm EST) ciclhelp@amc.org
The Cancer Information and Counseling Line (CICL) is a toll-free telephone service for cancer survivors, family members and friends, and the public. Professional counselors provide medical information, emotional support, and resource referrals to callers nationwide. If you leave a message they will return your call within 24 hours.

Children's Oncology Group
www.survivorshipguidelines.org/
The Children's Oncology Group provides guidelines and recommendations about long-term follow-up for cancer survivors. There is information available about different diagnoses, possible side effects from treatment, co-occurring conditions, finances, late effects, and emotional issues.

Fertile Hope
fertilehope.org
866-965-7205
A national nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

First Descents
www.firstdescents.org/ 303-945-2490
First Descents provides opportunities for 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. First Descents provides all necessary gear and equipment for the adventures. First Descents programs are free of charge for first-time participants. All cancer fighters and survivors ages 18-39 are eligible.

GET EMPOWERED: Life, Living & Follow-Up Care After Cancer
http://cancer.northwestern.edu/empowered/
Videos available on Youtube: http://www.youtube.com/playlist?list=PLJYcr5PhvTtt-aASjcsSTen1zHpV_PW
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 health care; cardiac risk factors; prevention and late effects; fertility; and finding a “new normal” and navigating the emotional side of survivorship. The videos feature 7 survivors sharing their own experiences, as well as survivorship care providers contributing their expertise. They emphasize the cancer journey, and each ends with a list of relevant resources.

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Children's Brain Tumor Foundation's Family 2 Family Program
www.cbtf.org/connections/family-2-family
866-228-4673
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/
877-274-5529
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 mentor is available to answer personal questions and offer unique support. 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.

I’m Too Young For This! Cancer Foundation/Stupid Cancer
www.stupidcancer.org
I’m Too Young For This! Cancer Foundation is a national, survivor-led advocacy, support and research organization that works on behalf of young adult survivors of cancer under age 40. They use music, arts and media to encourage survivors to talk openly about cancer. Services offered include: a radio show, scholarship information and free educational workshops on fertility, legal, and social issues. They also hold a large annual conference, the OMG! Cancer Summit for Young Adults.

Journey Forward
journeyforward.org/
Journey Forward is a program designed for cancer survivors and their doctors. Journey Forward promotes the use of Survivorship Care Plans. These plans, completed by the survivor’s oncology team, give clear steps for care after active treatment. A typical plan begins with a simple yet complete treatment summary and offers guidelines for monitoring future care.

Leukemia & Lymphoma Society (LLS)
www.lls.org/
The LLS has local chapters throughout the U.S. and Canada that have events and 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 such discussion board 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 survivorship issues. This chat group is open for you to discuss any issue related to living with leukemia, lymphoma or myeloma: a new diagnosis, treatment decisions, relapse, treatment side effects, emotional toll, fatigue, interpersonal relationships, clinical trials, living with uncertainty and other survivorship issues. YAconnect is every Tuesday evening, 8:30 p.m. to 10:30 p.m. EST.

Eastern Pennsylvania Chapter
www.lls.org/epa
Eastern Pennsylvania location: 610-238-0360
555 North Lane, Conshohocken, PA 19428
Lehigh Valley location: 610-266-8513
961 Marcon Blvd. Suite 452, Allentown, PA 18109

Central Pennsylvania Chapter
www.lls.org/cpa
717-652-6520
2405 Park Drive, Harrisburg, PA 17110

Western Pennsylvania Chapter
www.lls.org/wpa
412-395-2873
River Walk Corporate Centre, Pittsburgh, PA 15219

New Jersey Chapter
www.lls.org/nj
Cranford Location: 908-956-6600
14 Commerce Drive, Cranford, NJ 07016
Southern NJ Location: 856-638-1250
528 B Fellowship Rd, Mount Laurel, NJ 08054

Delaware Chapter
www.lls.org/de
302-661-7300
100 West 10th Street, Wilmington, DE 19801

Patti Robinson Kaufmann First Connection Program
www.lls.org/content/nationalcontent/resourcecenter/freeducationmaterials/services/pdf/firstconnection.pdf
This program matches patients with blood cancers and families with trained peer volunteers in their area. To be matched or to volunteer, contact your local Leukemia & Lymphoma Society office, or call the main center at 1-800-955-457.

Survivorship Website
www.lls.org/#/diseaseinformation/managingyourcancer/survivorship/
The Leukemia & Lymphoma Society’s survivorship website offers information and guidelines about what to expect and how to handle life after cancer.

LIVESTRONG Foundation
512-236-8820
1-866-235-7205 (LIVESTRONG SurvivorCare)
www.livestrong.org

Young Adult Alliance
www.livestrong.org/yaa
This foundation, started by Lance Armstrong, provides information about managing the physical and emotional effects of cancer and its treatment. Their website has helpful guides and worksheets, and stories from other survivors. LIVESTRONG SurvivorCare is a one-on-one support program where survivors can get counseling and referrals to local resources, and help with financial, insurance, and employment issues. The Young Adult Alliance advocates for young adults with cancer and survivors.

Mayo Clinic
www.mayoclinic.com/health/cancer-survivor/CA00061
Part of Mayo Clinic’s mission is to provide reliable health information. This website provides up to date medical information and research that can help patients and survivors understand their diagnoses, treatment, and late effects.

My OncoFertility
myoncofertility.org/
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.

National Brain Tumor Society
www.brain tumor.org/patients-family-friends/find-support/800-934-2873
The National Brain Tumor Society provides a web community for support for patients, survivors, friends, and family of brain tumors. The site helps to locate local support groups and provides resources specifically for adolescents and young adults who have survived a brain tumor.

National Cancer Institute Office of Cancer Survivorship (OCS)
dccps.nci.nih.gov/OCS/
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.

National Childhood Cancer Foundation
www.curesearch.org
1-800-458-6223
The website provides information for cancer patients at all stages of treatment and survivorship. Information is available for patients, families, and communities.

National Children’s Cancer Society (NCCS)
www.thenccs.org
The mission of the National Children’s Cancer Society 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 (for example, fertility concerns, insurance issues).
Psychosocial Services

National Coalition for Cancer Survivorship
www.canceradvocacy.org
301-650-9127 or 888-650-9127
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. Patient education is also a priority.

National Collegiate Cancer Foundation (NCCF)
http://collegiatecancer.org/survivorship
The National Collegiate Cancer Foundation 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.

Navigating Cancer Survivorship
www.NavigatingCancerSurvivorship.org
JM@NavigatingCancerSurvivorship.org
Twitter: @CancerRights
Facebook: www.Facebook.com/NavigatingCancerSurvivorship
Joanna Fawzy Morales, Esq. is a cancer rights attorney and CEO of Navigating Cancer Survivorship, a national nonprofit organization that provides education and resources on the entire continuum of cancer survivorship issues to survivors, caregivers, and healthcare professionals.

Next Step
www.nextstepnet.org
617-864-2921
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. The CARE Program consists of two-day retreats for adolescents and young adults affected by illness in addition to involving their parents or caregivers in the retreats.

Patient Advocate Foundation (PAF)
www.patientadvocate.org
1-800-532-5274
The Patient Advocate Foundation (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.

Patient Centered Guides, Childhood Cancer Survivors
Provides information regarding legal rights, referral services, Individual Education Programs (IEPs), Individual Transition Plans (ITPs), job training, college, and paying for college.

Pediatric Oncology Resource Center
www.ACOR.org/ped-onc/survivors/index.html
The Pediatric Oncology Resource Center is a site for parents, friends, and families of children who have or have had childhood cancer. Information on survivorship includes long-term medical, psychological, and neurocognitive problems due to chemotherapy, radiation or surgery.

Planet Cancer
http://myplanet.planetcancer.org
Planet Cancer provides programs for young adults diagnosed with cancer and outreach to the medical community about the unique needs of young adults. Planet Cancer provides numerous resources including articles, comics, games, personal stories, and information about grants and scholarships. Planet Cancer offers weekend retreats with others in the same age group.
Prepare to Live (P2L)
www.preparetolive.org/
Prepare to Live is a non-profit organization founded and managed by cancer survivors, dedicated to provide Help, Hope, Information and Inspiration™ specifically to young adults coping with cancer worldwide. Their goal is to produce two films every 2-3 years (one for patients — “Prepare to Live,” the other for caregivers — “Prepare to Care”). The website also offers news articles, columns, health-related books, forums, blogs, events and a directory of web links.

Re-Mission
www.re-mission.net
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
Provides support for young adults affected by breast cancer. Survivors can volunteer to provide peer support to young women recently diagnosed with breast cancer.

Rise to Action Survivors Program: Children’s Cause for Cancer Advocacy
301-562-2765
www.childrenscause.org/programs/rta
Rise to Action is a two-day conference focused on education and leadership development for survivors (age 18-25) and teaches survivors how to manage follow-up care and act as advocates.

River Discovery
www.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.

Sharsheret
www.sharsheret.org/how-we-help/young-women/survivors
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. Offers opportunities to connect with other young survivors, join a peer support network, and join teleconferences and online seminars hosted by experts.

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

Teens Living With Cancer: A Project of Melissa’s Living Legacy
www.teenslivingwithcancer.org/
Teens Living With Cancer provides information about cancer and survivorship through a web-based community. The message board allows survivors to share their stories and support each other. The site has information about how to remain healthy after cancer treatment has ended.

True North Treks
www.truenorthtreks.org
Dedicated to enriching the lives of adolescent and young adult cancer survivors through contemplative and outdoor-based activities.

Ulung Cancer Fund for Young Adults
www.ulmanfund.org
info@ulmanfund.org
The Ulman Cancer Fund provides a comprehensive support program for Young Adults affected by cancer. It offers social support services, a trial matching service, college scholarships, resources such as, “Survival Guide, No Way It Can’t Be: A Guidebook for Young Adults Facing Cancer,” a speakers’ bureau, and a Patient Advocate/Navigator Program.
Vital Options International
www.vitaloptions.org/
818-508-5657

Vital Options International is an organization designed to create discussion around the world about cancer, so people around the world can share their stories, support, and resources. The program allows patients and loved ones to interact directly with oncology leaders about treatment, research, advocacy, and public policy. The website additionally provides a number of resources, including information about cancer-related radio broadcasts. Additionally, there is a message board which allows communication among all cancer patients, survivors, and loved ones.

Young Adults Surviving Glioblastoma
www.yasg.com

This website has many personal stories of young adults that have survived glioblastoma. It also has an active discussion forum, on which patients and survivors discuss their experiences and exchange advice.

Health Promotion Information and Resources

Survivorship Apps and Patient Portals

AYA Healthy Survivorship App
http://www.healthysurvivorship.org/
Or search “AYA Healthy Survivorship” in the iTunes store to download the app for free

This app is designed specifically for the needs of adolescent and young adult (AYA) cancer survivors ages 15-39. You can take a Healthy Survivorship Assessment to see how you’re doing, and see what areas you can improve to live a healthier life. You can also input your survivorship plan to keep track of what screenings you need, or create a survivorship plan if you don’t have one. The app includes information about screening and late effects, as well as tips for exercising and healthy eating. You can even sign up for daily tip alerts and connect to other survivors through the app.

The app also links to the Children’s Oncology Group guidelines in English and Spanish.

Cancer SurvivorLink™

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.

Improving Sleep

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

National Sleep Foundation
www.sleepfoundation.org/sleep-facts-information/sleeping-smart

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.

WebMD Sleep Tips for Teens
teens.webmd.com/features/8-ezzz-sleep-tips-teens

This article has tips for adolescents on how to get better sleep, and explains why getting enough sleep is important.

Information and Tips:

Many adolescents and young adults do not get enough sleep. The average amount of sleep that they get is between 7 and 7.25 hours. However, studies show that 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 to 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 is 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, such as reading a book, listening to a calming play list, dimming the lights, or drinking a cup of chamomile tea, when done regularly, help your body and mind slow down and let your body know it is time for sleep. Do not watch TV, study, or get involved in “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.


**Being Active**

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

- Do something you enjoy — the best way to make sure you will stay active is to find something that 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.

- 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 http://lombardi.georgetown.edu/pediatric/survivorship/handbook.html
The following organizations and websites provide information about staying healthy in general and monitoring for secondary cancers. Some of these websites may be interesting to adolescents and young adults who are not survivors, too.

**American Cancer Society (ACS)**

[www.cancer.org/treatment/survivorshipduringandafter treatment/index](http://www.cancer.org/treatment/survivorshipduringandafter treatment/index)

Nationwide: 1-800-227-2345


The website provides information on health promoting behaviors (such as eating healthy and staying active), ways to screen for cancer, and resources for survivors.

**Boarding for Breast Cancer**

[www.b4bc.org](http://www.b4bc.org)

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

**Colon Club**

[www.colonclub.com](http://www.colonclub.com)

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

**Sean Kimerling Testicular Cancer Foundation**

[www.seankimerling.org](http://www.seankimerling.org)

Dedicated to increase early detection of testicular cancer and providing information on regular self-examination.

**The Next Step: Crossing the Bridge to Survivorship**

[lombardi.georgetown.edu/pdf/micro/peds/survivorship/Next-Step_Section5_HealthyChoices.pdf](http://lombardi.georgetown.edu/pdf/micro/peds/survivorship/Next-Step_Section5_HealthyChoices.pdf)

The Healthy Choices as a Lifestyle section of this survivorship handbook provides tips for healthy living, such as eating well and physical activity.

**Smoking Cessation**

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

**American Cancer Society**

[www.cancer.org/Healthy/StayAwayfromTobacco/GuidetoQuittingSmoking/index](http://www.cancer.org/Healthy/StayAwayfromTobacco/GuidetoQuittingSmoking/index)

Provides information and tips on quitting smoking.

**Delaware Quitline**

[www.dhss.delaware.gov/dhss/dph/dpc/quitline.html](http://www.dhss.delaware.gov/dhss/dph/dpc/quitline.html)

1-866-409-1858

Tobacco 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 Delaware Quitline is free, and serves Delaware residents ages 18 and older.

**Help Teens Quit**

[www.helpteensquit.com/](http://www.helpteensquit.com/)

Help Teens Quit provides information, tools, and handouts to help teens and young adults quit smoking.

**NCI QuitPal Mobile App**


The National Cancer Institute developed a mobile app, using proven quit strategies and tools, to help you change behavior and give up smoking. By downloading NCI QuitPal for free from the App Store to your iPhone or iPad, you can instantly get help to quit smoking, right at your fingertips. Among other features, the NCI QuitPal tracks daily smoking habits, includes motivational reminders that coincide with progress, and allows users to connect with social networks and view personalized video messages from loved ones.
New Jersey Quitline
www.njquitline.org/
1-866-NJSTOPS (1-866-657-8677)
NJ 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 8:00 a.m. to 3:00 a.m., and if you call after hours you can leave a voicemail or listen to tips for quitting smoking.

Pennsylvania Free Quitline
https://pa.quitlogix.org
1-800-784-8669
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 speak to a coach by phone as well. They also offer a free 2-week supply of patches or gum.

Quit for Health Research Programs at Penn
www.med.upenn.edu/cirna/quit_for_health.shtml
Provides information about ongoing research studies on quitting smoking through the University of Pennsylvania. Some studies include free counseling and skills trainings, and all provide compensation for participation.

Smoke-Free Philly
smokefreephilly.org
215-246-5584
Smoke-Free Philly matches you with a quit coach to help stop smoking. There are also groups designed for 18-25 year olds. The website provides handouts and tools to help quit smoking.

Stop Smoking Now!
610-738-2300
A free seven-week cessation program, Stop Smoking Now!, helps you develop a plan to become a nonsmoker. Through a combination of education, behavior modification, and relaxation techniques, this program teaches you the tools you need to take this important step. You can receive Over-The-Counter Nicotine Replacement Therapy (NRT) (nicotine patch) at no charge. Call or visit the website to see upcoming start dates of the program, offered at various Penn-affiliated locations.

Books
The following books (some of which are available online for free) provide information on many aspects of survivorship. Some were written by adolescent and young adult survivors of cancer.

General
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.

By Honna Janes-Hodder & Nancy Keene
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. Emotional and psychological issues are addressed as well, with personal accounts to help parents and families cope with daily stress or in the event of death.

Childhood Cancer Survivorship: Improving Care and Quality of Life
By Maria Hewitt & Susan L. Weiner
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.
By Nancy Keene
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
The book contains black-and-white illustrations and addresses the unique survivorship issues facing the adolescent with cancer.

Twice: How I Became a Cancer-Slaying Super Man Before I Turned 21
By Ben Rubenstein
Author’s Blog: www.cancerslayerblog.com
Amazon Preview: www.amazon.com/TWICE-Became-Cancer-Slaying-Before-Turned/dp/0978647297
This book is written by a young adult that survived cancer twice — first at 16, and again at 19. Please note that this book is appropriate for young adults, but is graphic and not appropriate for younger children.

Walking with a Shadow: Surviving Childhood Leukemia
By Nancy A. Sullivan
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.

THRIVE/SURVIVE eBook
www.thrivesurvive.org/
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 eBook 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 eBook is supplied by experts, leaders and organizations in the cancer community. If you fill in your email address on the website, they will email you a free, downloadable PDF copy of the book.

Academic/Learning-focused Resources

Educating the Child with Cancer: A Guide for Parents and Teachers
By Nancy Keene
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.

By Princeton Review
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
Peterson’s Guide to Colleges with Programs for Learning-Disabled Students
By Charles Mangrum & Stephen Strickart
Provides a list of colleges that have “comprehensive” or “special services” for students with learning disabilities.

Self-Advocacy Skills for Students with Learning Disabilities: Making It Happen in College and Beyond
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.
Founded in 1855, The Children’s Hospital of Philadelphia is the birthplace of pediatric medicine in America. Throughout its history, a passionate spirit of innovation has driven this renowned institution to pursue scientific discovery, establish the highest standards of patient care, train future leaders in pediatrics, and advocate for children’s health. A haven of hope for children and families worldwide, CHOP is a nonprofit charitable organization that relies on the generous support of its donors to continue to set the global standard for pediatric care.

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