

Finding and Paying for Healthcare

As a childhood cancer survivor, it is important for you to have regular medical check-ups, since some of the treatments that you received may increase your risk for health problems as you get older. Sometimes it is difficult to find and pay for the medical care that you need. There are several things you can do to make sure you are getting the best possible care for your needs. Here are some suggestions.

If possible, find a long-term follow-up clinic. Many childhood cancer programs have long-term follow-up clinics. A directory of long-term follow-up clinics affiliated with Children's Oncology Group institutions can be found at this link: <https://www.cogmembers.org/public/lateeffects/default.aspx>. If you are still followed in a childhood cancer center, or if there is a childhood cancer center near where you live, contact that center to discuss your options for obtaining long-term follow-up care. Long-term follow-up clinics usually screen for late effects and educate survivors about ways to lower the risk of health problems after cancer. They are generally an excellent place to get a complete health evaluation, but are not usually designed to meet the everyday healthcare needs of survivors and may only see survivors until they reach adulthood. Even if you are attending a long-term follow-up care clinic, it is also important to find a primary healthcare provider who can take care of your general medical needs.

Choose a primary healthcare provider in your community. The best primary healthcare providers for adults are usually those who specialize in family practice or internal medicine. The chance of finding a primary healthcare provider who has experience taking care of childhood cancer survivors is low, due to the rarity of cancer in children. However, it is important to look for a healthcare provider who is thorough, well-trained, and a good listener. Ask friends and family members to help you identify healthcare providers with these qualities who are practicing in your area. Make an appointment for a general check-up and discuss your past medical history and health risks during this visit. It is best to do this introductory visit at a time when you are well, and not when you are being seen because of an illness.

Tell your healthcare provider about the Childhood Cancer Survivor Long-Term Follow-Up Guidelines, available on the Children's Oncology Group website at www.survivorshipguidelines.org. This comprehensive set of healthcare screening and management guidelines is designed for use by healthcare professionals who are providing ongoing medical follow-up for childhood cancer survivors.

Organize a medical team to provide your local care. Get advice from your childhood cancer doctor and your primary healthcare provider about who should be on your medical team. Your team should always include a primary healthcare provider and a dentist. Depending on your situation, you may also need to include other professionals that are important for your continued health, such as a physical therapist or psychologist. Your primary healthcare provider can help you select these individuals and provide referrals for their services.

Share your medical records with all the members of your medical team. If possible, ask the oncologist who treated your childhood cancer to provide you with a survivorship care plan that includes a summary of your diagnosis and treatment, future health risks, and recommended screening. Ask your oncologist to share a copy of your treatment summary with all your healthcare providers. Keep a copy of the care plan and important sections of your pediatric medical records in a personal medical file. Be sure that every new healthcare provider you see is aware of your medical history and any special health risks you may have because of your cancer treatment. If you need help in obtaining your medical records, call the hospital, clinic, or medical center where you received your treatment.

Be a partner in the healthcare that you receive. To find out if you are getting adequate care, ask yourself the following questions:

- Do I know my cancer diagnosis and specific treatment I received?
- Do I know about the health problems that can occur after this treatment?
- Have I shared this information with my healthcare providers?
- Does my healthcare provider check periodically for health problems specifically related to my childhood cancer?
- Does my healthcare provider advise me about things I should or should not do to keep healthy after my treatment for childhood cancer?

Explore all resources for paying for healthcare. Healthcare is expensive and people who have had a serious illness often face many hurdles when trying to obtain adequate follow-up care. In the United States, insurance companies are now required to provide coverage for childhood cancer survivors, regardless of pre-existing medical conditions. The law also now provides the option of coverage under a parent's health insurance policy for young adults under age 26. More information about your rights and protections under the health care law (commonly known as the "Affordable Care Act"), is available at this link: <https://www.healthcare.gov/health-care-law-protections/>. If you aren't insured, you should seek assistance from a local social service organization or your hospital social worker to identify your coverage options.

As a survivor of childhood cancer, you have already overcome many obstacles. The process of obtaining and paying for healthcare can sometimes seem discouraging, but it is worth the effort.

Survivorship Healthcare Coverage Checklist

Define your current healthcare needs. Ask yourself:

- Do I mainly need a healthcare provider for general check-ups?
- Do I have chronic health problems that require frequent medical visits?
- Do I have problems that need periodic monitoring by specialists?
- Am I on expensive prescription medications?
- Do I require prosthetic or rehabilitation services?

Explore all resources for healthcare coverage:

- Coverage through a parent's or spouse's policy
- Health insurance coverage offered by your college or employer
- State or federal public assistance programs that may substantially lower the cost of coverage
- Discounted or free healthcare through health department clinics or church-based programs
- Low cost or free prescription programs provided by some pharmaceutical companies for people with low income

If you are insured, get the facts about your policy.

- What services are covered?
- Does your plan offer a discounted prescription program?
- Are referrals to specialists controlled through a primary care physician?
- Is coverage in effect only while the patient is a full-time student?
- Does coverage expire at certain age?

Ask for help in understanding current resources and locating new ones.

- Ask family members, friends, hospital or clinic insurance managers, and insurance representatives to explain unclear details about insurance benefits.
- Call a clinic or hospital social worker to ask for help in finding state or community healthcare resources.
- Check out services offered by national nonprofit organizations (example, Lions Club for ocular prostheses).
- Be proactive in obtaining and maintaining health insurance coverage.
- Visit www.healthcare.gov to determine your options for insurance coverage and to determine whether you qualify for discounted or free coverage available to people with low income or disability.
- Avoid lapses in coverage. Plan for transitions in health insurance coverage that occur with college graduation, aging out of parental coverage, or job changes.

Be aware of the laws that help you keep insurance benefits. The following laws apply to survivors living in the United States:

- **ACA** (Affordable Care Act), the comprehensive health care reform law enacted in the United States on March 30, 2010, created a Health Insurance Marketplace and new rights and protections that make health insurance coverage fairer and easier to understand. More information is available at www.healthcare.gov.
- **COBRA** (Consolidated Omnibus Budget Reconciliation Act) requires employers or larger businesses to make insurance available for a limited time to employees (and their dependents) who are fired or laid off.
- **HIPAA** (Health Insurance Portability and Accountability Act of 1996) allows people with pre-existing conditions to keep comprehensive insurance coverage when they are changing insurance plans or jobs. Under the new Health Care Law in the United States, HIPAA eligibility provides greater protections than are otherwise available under state law.

Be persistent when meeting obstacles. Try not to get overwhelmed.

- Complete and follow through with applications.
- Appeal denials with letters of support from your healthcare provider.
- Contact groups such as Candlelighters and the National Coalition of Cancer Survivors for more information about healthcare resources.

Recommended Resources

The National Coalition of Cancer Survivors is a patient-led advocacy organization for cancer survivors. Their website, www.canceradvocacy.org, lists organizations and agencies that offer help regarding specific cancer-related issues, including finding affordable healthcare. Their phone number is (877) 622-7937.

Cancer Care, a nonprofit organization dedicated to providing emotional support, information, and practical help to people with cancer and their loved ones. Their site also has a searchable database to assist in finding local and national resources to help with financial and practical needs. 1-800-813- HOPE (4673) www.cancer.org.

Written by: Melissa M. Hudson, MD, St. Jude Children's Research Hospital, Memphis, TN; Sally Wiard, MSW, LCSW, Children's Hospital of San Antonio, San Antonio, TX; and Allison Hester, RN, MSN, CPNP, Arkansas Children's Hospital, Little Rock, AR. Adapted from the CCSS Newsletter, Spring 2003, used with permission.

Reviewed by Amelia DeRosa RN, BSN, CPON; Christine S. Yun, MSN, PNP, CPON; and Kayla L. Foster, MD, MPH.

Additional health information for childhood cancer survivors is available at
www.survivorshipguidelines.org

Note: Throughout this *Health Links* series, the term “childhood cancer” is used to designate pediatric cancers that may occur during childhood, adolescence, or young adulthood. Health Links are designed to provide health information for survivors of pediatric cancer, regardless of whether the cancer occurred during childhood, adolescence, or young adulthood.

Disclaimer and Notice of Proprietary Rights

Introduction to Late Effects Guidelines and Health Links: *The Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* and accompanying *Health Links* were developed by the Children's Oncology Group as a collaborative effort of the Late Effects Committee and Nursing Discipline and are maintained and updated by the Children's Oncology Group's Long-Term Follow-Up Guidelines Core Committee and its associated Task Forces.

To cancer patients (if children, their parents or legal guardians): Please seek the advice of a physician or other qualified health provider with any questions you may have regarding a medical condition and do not rely on the Informational Content. The Children's Oncology Group is a research organization and does not provide individualized medical care or treatment.

To physicians and other healthcare providers: The Informational Content is not intended to replace your independent clinical judgment, medical advice, or to exclude other legitimate criteria for screening, health counseling, or intervention for specific complications of childhood cancer treatment. Neither is the Informational Content intended to exclude other reasonable alternative follow-up procedures. The Informational Content is provided as a courtesy, but not intended as a sole source of guidance in the evaluation of childhood cancer survivors. The Children's Oncology Group recognizes that specific patient care decisions are the prerogative of the patient, family, and healthcare provider.

No endorsement of any specific tests, products, or procedures is made by Informational Content, the Children's Oncology Group, or affiliated party or member of the Children's Oncology Group.

No Claim to Accuracy or Completeness: While the Children's Oncology Group has made every attempt to assure that the Informational Content is accurate and complete as of the date of publication, no warranty or representation, express or implied, is made as to the accuracy, reliability, completeness, relevance, or timeliness of such Informational Content.

No Liability on Part of Children's Oncology Group and Related Parties/Agreement to Indemnify and Hold Harmless the Children's Oncology Group and Related Parties: No liability is assumed by the Children's Oncology Group or any affiliated party or member thereof for damage resulting from the use, review, or access of the Informational Content. You agree to the following terms of indemnification: (i) “Indemnified Parties” include authors and contributors to the Informational Content, all officers, directors, representatives, employees, agents, and members of the Children's Oncology Group and affiliated organizations; (ii) by using, reviewing, or accessing the Informational Content, you agree, at your own expense, to indemnify, defend and hold harmless Indemnified Parties from any and all losses, liabilities, or damages (including attorneys' fees and costs) resulting from any and all claims, causes of action, suits, proceedings, or demands related to or arising out of use, review or access of the Informational Content.

Proprietary Rights: The Informational Content is subject to protection under the copyright law and other intellectual property law in the United States and worldwide. The Children's Oncology Group retains exclusive copyright and other right, title, and interest to the Informational Content and claims all intellectual property rights available under law. You hereby agree to help the Children's Oncology Group secure all copyright and intellectual property rights for the benefit of the Children's Oncology Group by taking additional action at a later time, action which could include signing consents and legal documents and limiting dissemination or reproduction of Informational Content.