

Finding and Paying for Healthcare after Treatment for Childhood Cancer

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. If you are still followed in a childhood cancer center, or if there is a childhood cancer center near where you live, call them and find out if they have a long-term follow-up program. 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. Also, some long-term follow-up programs are only able to follow survivors until they reach adulthood, which may mean that they can see survivors only until they reach age 18 or 21. So, even if you are attending a long-term follow-up 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 serious illnesses like 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 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. Ask your hospital or clinic to send copies of your treatment records to all of your new healthcare providers. If possible, ask the doctor who treated your childhood cancer to provide you with a summary of your diagnosis and treatment, future health risks, and recommended screening. Keep a copy of the summary 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 insurance coverage. However, you may still be able to get insurance, even with your health history. Milestones of five, seven, and ten years from the end of treatment seem to be important to insurers. Ask your healthcare provider to write a letter to the insurance company documenting your long-term remission.

If you aren't insured, you should seek assistance from social service organizations or social workers to identify possible programs to help you obtain low cost insurance. There may be State or Federal public assistance programs that you may qualify for. If you need medical care and currently do not have insurance, you can talk to your healthcare provider about arranging a payment plan for primary care services. You may be able to have lab work done for a reduced rate at your county or city health

department. If you need an evaluation by a specialist or an expensive test, ask your healthcare provider if you can be referred to a medical specialist or facility that offers discounted rates or payment plans for individuals who are uninsured.

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 rehab services?

Explore all resources for healthcare coverage:

- Private insurance coverage through a parent's or spouse's policy
- Health insurance coverage offered by your college or employer
- State or federal public assistance programs
- 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 incomes

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?
- Are limitations set on pre-existing medical conditions?
- 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.
- Contact your state insurance office to get a list of insurance providers in your state.
- Call your county department of human services to find out if you qualify for healthcare through state or federal programs for people with low income or disability.
- Avoid lapses in coverage. Plan for transitions in health insurance coverage that occur with college graduation 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:

- **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. Certain conditions apply that may limit the help available to you under HIPAA. Contact your social worker, insurance provider, or state insurance department with questions.

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.
- Don't give up!

Recommended Resources:

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

HIPAA. Information about the Health Insurance Portability and Accountability Act of 1996, which helps people with pre-existing health conditions get and keep health insurance, is available on the website of the U.S. Department of Health and Human Services at: <http://cms.hhs.gov/hipaa/hipaa1/content/cons.asp>.

Candlelighters Childhood Cancer Foundation® (CCCCF) is a non-profit organization whose mission is to educate, support, serve, and advocate for families of children with cancer and childhood cancer survivors. www.candlelighters.org. 800-366-CCCCF (800-366-2223).

Cancer Care, a nonprofit organization dedicated to providing emotional support, information, and practical help to people with cancer and their loved ones. 1-800-813-HOPE (4673). www.cancercares.org.

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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.

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