Late Effects after Amputation for Childhood Cancer

Treatment for a childhood bone or soft tissue tumor of the arms or legs may include an amputation as part of the treatment. Sometimes an amputation is needed because of complications, such as an infection. This Health Link will focus on the possible late effects from amputation due to childhood cancer.

What are the potential late effects of amputation?

- Skin blisters, redness, or bruising from a poorly fitting prosthesis
- Phantom limb pain (perception of pain coming from the area where the limb used to be)
- Shooting pains, severe cramping, or a burning sensation in the amputated limb
- Skin breakdown and slow wound healing of the remaining limb
- Back or other muscle pain (due to increased use of other muscle groups and limbs to make up for decreased function in the amputated extremity)
- Emotional distress related to change in body image
- Increased energy or effort to do daily activities
- Increased weight gain (due to decreased physical activity)
- Development of diabetes (because of weight gain, lack of physical activity and poor food choices)

What are the follow-up recommendations for amputees?

- Keep the residual limb clean and dry
- Check the skin daily for color changes and skin break down
- Wash items that are used in the prosthesis (stump shrinker, elastic garments, stump socks) regularly
- Have an evaluation of the prosthesis fit every 6 months until you are fully grown, then once a year, and any time problems arise
- Work with a physical and occupational therapist to develop a plan for gait training, activities of daily living, and an exercise plan (including range of motion, strength, agility, and balance)
- Have a yearly physical examination
- Maintain a healthy diet and activity level

What are the signs that your prosthesis needs the attention of a prosthetist?

- You hear noises of any kind (squeaking, popping, clicking, etc.)
- You break any part of the prosthesis
- You need new supplies



- You have outgrown the prosthesis
- You have chronic pain while wearing your prosthesis

What other issues occur after amputation?

- Dealing with peer pressure and body image change
- Coping with "being different"
- Feeling anxious, unsure, or sad
- Paying for a new prosthesis
- Coping with environments that may or may not be accessible
- Using public transportation (airplane, train, bus, etc.)
- In some cases, living with chronic pain (see related Health Link: Chronic Pain after Childhood Cancer)

Where can I get help?

Talk with your healthcare provider regularly to let them know of any difficulties that you may be facing. In addition, the following web sites offer resources for amputees:

- <u>www.amputee-coalition.org/first_step/firststepv2_toc.html</u>
 Provides information about "First Step, A Guide for Adjusting to Limb Loss" published by the Amputee Coalition of America.
- <u>www.amputee-coalition.org</u> Provides further resources for education, advocacy and peer support for amputees. The first step program above is part of the ACA.

Written by Tori Marchese, PhD, PT, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, Memphis, TN, Rajaram Nagarajan, MD, MPH, Pediatric Hematology/Oncology/BMT, University of Minnesota Cancer Center, Minneapolis, MN, and Tom Baker, CP (certified prosthetist), CFI, Memphis, TN.

Reviewed by Revonda Mosher RN, MSN, CPNP, CPON[®], Melissa M. Hudson MD, and Joan Darling PhD.

Reference: Lusardi MM, Nielsen CC, <u>Orthotics and Prosthetics in Rehabilitation</u>, Butterworth-Heinemann, Boston, 2000.



Additional health information for childhood cancer survivors is available at <u>www.survivorshipguidelines.org</u>

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 excursive 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.



Copyright 2008 © Children's Oncology Group All rights reserved worldwide