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:

• www.amputee-coalition.org/first_step/firststepv2_toctoc.html
  Provides information about "First Step, A Guide for Adjusting to Limb Loss" published by the Amputee Coalition of America.
• www.amputee-coalition.org
  Provides further resources for education, advocacy and peer support for amputees. The first step program above is part of the ACA.

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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.

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