

FACT SHEET 3

Acquired Limb Differences

A person with an acquired limb difference has had an amputation to remove all or part of a limb. This differs from congenital limb difference (where a child is born with a limb difference) although sometimes a congenital limb difference leads to an amputation or reconstruction following a child's birth. Generally, however, a limb amputation is required because of trauma (such as an accident) or an illness.

This Fact Sheet contains information to help you if your child has or will be having a limb amputation including: adjusting to your child's limb difference; assisting your child; and, accessing support.

Adjusting to your child's limb difference

An acquired limb difference will be life changing for your child, yourself, siblings, family members and friends. It will also be a change that, if your child is in school, will also affect your child's educators and school friends.

Sometimes a child and their family know in advance that they will be having a scheduled limb amputation; allowing time for families to prepare for this surgical procedure. In this instance you and your family may have had time to access information, been part of the planning with medical professionals and able to discuss the scheduled amputation with your child and others in your life.

At other times a child's amputation may occur suddenly because of an emergency and sometimes the amputation may be a life saving measure. In this case you may not have had time to access information or engage in the decision making made by the medical team.

Parents of children with an acquired limb difference often report an array of conflicting emotions. We understand that learning your child is going to or has had a limb amputation means there will be lots of information to take in and naturally you might feel overwhelmed, concerned, upset and have lots of questions. In some cases, and particularly when your child has lost a limb due to an emergency, you may also feel relief and thankfulness.

Regardless of the circumstance, adjusting to your child's limb difference means that you may find yourself on a rollercoaster of emotions. You may find yourself experiencing a sense of grief and feel worried about the lifelong impact that the limb difference will have on your child. You may also feel overwhelmed because you know little about limb difference, don't know what to expect, don't know how it will affect your child and family and not sure how others will react. These feelings generally subside over time and you should not feel guilty about the way you are feeling.

You are also likely to be overwhelmed supporting your child, who has just gone through a significant experience. Your child may still be in hospital or at home recovering and it is important to support your child as he or she adjusts to their limb difference. Every child responds differently to this physical change. It is important to reassure your child, explain to them what has happened (or what will happen if an amputation is scheduled) and the reasons why it is happening. If possible, try to ensure communication with your child, any siblings and within your family remains open and honest.

Assisting your child

Understanding what your child has or is experiencing will help you to assist him or her. A limb amputation is a major body change and your child will need to adjust physically and emotionally.

Physical adjustments

A limb amputation can often be accompanied by significant physical adjustments for a child. Your child will need to heal from the surgery, participate in physical activity and return to their normal activities. The physical adjustments often depend on the site and level of amputation. Your child will need to work on regaining muscle strength, coordination and balance. Your child will need to learn to adjust to managing everyday activities; whether that is with or without a prosthesis.

Physical adjustments can take time and impact on not only your child but also your family. Learning to function with a prosthesis can be tiring but with hard work, perseverance, support and encouragement from your family and the medical team your child will successfully adjust to these changes.

Emotional adjustments

A limb amputation can often lead to emotional adjustments for a child. The type of amputation does not dictate how a child will react - each child will respond in their own personal way.

Your child may feel worried, sad, experience fear or uncertainty about what the future might hold. Your child might also feel nervous about returning to the activities he or she used to do. Your child may also be concerned about how siblings or peers might react to his or her limb difference. Your child may also feel worried about how you, as a parent, will react and adjust to their limb difference. All of these feelings are quite normal but it is important to allow your child to discuss their feelings with you. It is important to encourage your child to know it is safe to talk and ask questions.

As a parent you will be involved in many of the choices and plans regarding your child's rehabilitation and prosthetic planning choices. Where possible, try and include your child in these discussions and plans. Try and assist your child to understand what is going to occur during the recovery and rehabilitation period. You may also want to include a medical specialist in these discussions with your child.

Accessing support

Talking about your child's acquired limb difference can be very comforting and a good way of sharing any sadness, anxieties and concerns you may have. Keeping feelings to yourself can sometimes be damaging to your health and relationships, so try to keep open 'lines of communication' with others.

You may want to speak to a Limbs 4 Kids team member who can assist you. You may also want to speak to another parent who has experienced what you are going through. If so, Limbs 4 Kids can connect you to a trained Peer Support Volunteer who you can speak to you. Visit our website or call us for more information and links to our online support.

If you (or other members of your family) are not coping and could benefit from professional support there are many services that can assist you. You may want to speak to your GP, hospital Social Worker, Maternal Health Nurse or Paediatrician. You may also want to speak with an external counselling service such as:

Beyond Blue

www.beyondblue.org.au Tel: 1300 22 46 36

Lifeline

www.lifeline.org.au Tel: 13 11 14

Men's Line Crisis Support

www.mensline.org.au Tel: 1300 78 99 78

PANDA (Post and Antenatal Depression Association)

www.panda.org.au Tel: 1300 72 63 06

Parent Line

www.parentline.com.au Tel: 1300 30 1300