



Support for children and young people with limb differences and their families

FACT SHEET 1

About Limb Difference and Limb Difference Professionals

Limb difference is an overarching term used to describe any child or young person born with a congenital limb deficiency or who acquires limb loss after birth.

Children and young people with a limb difference can lead independent and successful lives and there are many well known people in our community, and around the world, who live with a limb difference.

Persons with a limb difference, whether they are a child or an adult, may choose to use a prosthetic limb. While others may decide not to or use other assistive devices instead.

In Australia it is estimated that close to 2,000 children and young people live with a limb difference. Two types of limb differences exist – congenital limb differences and acquired limb differences.

This Fact Sheet describes types of limb differences and the limb difference professionals that work with children, young people and their families.

Congenital limb difference

A number of different terms are used to describe children born with a congenital limb difference including 'Congenital Limb Reduction' or 'Congenital Limb Deficiency'. The term 'Dysmelia' is also used as an umbrella term for all types of congenital limb differences. In the medical community congenital limb differences are considered to be rare.

There are many different causes of congenital limb differences. Some causes are genetic, some are due to environmental or pharmaceutical factors, whereas others may be because of an isolated issue or syndrome occurring during foetal development. Often there is no known cause for a congenital limb difference.

Some children born with a congenital limb difference may undergo reconstructive surgery to allow a prosthesis to be fitted.

Information about various congenital limb difference conditions can be found on a number of credible medical websites including:

Orphanet:

www.orpha.net

WebMD:

www.webmd.com

National Centre for Biotechnology Information:

www.ncbi.nlm.nih.gov

Online Dysmelia Community:

www.dysnet.org

Acquired limb difference

A person with an acquired limb difference has had an amputation to remove all or part of a limb. A limb amputation might be required because of trauma (such as a car accident) or it might be due to illness (such as cancer or a severe infection).

Limb difference professionals

Whether your child is born with a congenital limb difference or acquires one during their life time, you are likely to meet with a team of health professionals who will work together to support you and your child. This is called a 'multi-disciplinary approach' to health care and means that a number of professionals will work collaboratively to achieve the best possible outcome for your child.

Sometimes you will meet with a group of professionals or meet with many different professionals one-on-one. This can be confusing and sometimes intimidating if you don't understand who each person is, why they are there and what they do. If you aren't sure who you are meeting, just ask them to explain who they are and what their role is. You are more likely to achieve a better outcome for your child if you have a better understanding of the services and support each professional can offer to you, your child and your family. Key professionals include:

Paediatric Rehabilitation Specialists or Consultants:

provide specialist care; coordinate the team and the clinic; help you to set goals and decide what's important in your child's life; and, monitor your child's growth and development with the rest of the team.

Prosthetists:

assess your child to decide which prosthesis (if any) will best suit your child's needs and mobility goals; design, fabricate and provide your child with their prosthesis; meet your child for regular reviews and adjustments; and, update or modify your child's prosthesis as they grow and develop.

Physiotherapists:

design programs to assist your child to meet their mobility goals; develop programs to suit your child's ability (eg. games, gym); provide advice to help you look after your child's residual limb; assist with activities to improve balance, flexibility and strength to help with mobility; and, work with your child's Prosthetist to help your child use a prosthesis (artificial limb).

Occupational Therapists:

help your child to achieve independence by providing assistance with daily living learning (such as dressing and eating); help to arrange access to assistive devices if required; provide specialist care to assist children with upper limb loss to use their prosthesis; assist your child to develop goals and action plans; and, liaise with schools regarding learning and accessibility issues.

Social Workers:

provide you and your family with confidential counselling; provide emotional support and assistance while adjusting to your child's limb difference; assist with sourcing government assistance (eg. financial, transport, parking permits); assist with accessing local community support and activities; and, liaise with schools regarding emotional or peer issues.

Maternal and Child Health Nurses:

are often available through state government departments or local councils; provide you with information, guidance and child health support; and, offer assistance whilst adjusting to parenthood.

Limb difference terminology

If you are the parent or carer of a child with limb difference you will enter a world that uses an array of unique words and terms. While some words may be familiar to you, many of the others used by medical professionals, clinicians and service providers can seem unfamiliar and new. Often the terms relate to medical conditions, body parts, prosthetics, aids and equipment. A comprehensive list of limb difference terms can be found on the Limbs 4 Kids website.