

FACT SHEET 2

Congenital Limb Differences

If you have been told prenatally (via a diagnostic test) that you are having a child with a limb difference, firstly congratulations on the impending arrival of your new baby.

Sometimes, however, limb differences are not picked up during routine pre-natal scans and it is only after a child is born that parents learn their child has a limb difference. If you have just given birth to a child with a limb difference we want to congratulate you on the birth of your beautiful new baby.

This Fact Sheet contains information that will assist you if you have been told you are having or have just given birth to a child with a congenital limb difference including: sharing news about your baby; your new baby; and, accessing support.

Hearing the news

We understand that learning your child has a limb difference means there will be lots of information to take in and naturally you might feel overwhelmed, concerned, upset and have lots of questions. It is not unusual to feel shock, sadness and grief when you learn that your child has a limb difference. In a way you may be mourning the loss of the baby you were expecting and it is important that you allow yourself time to adjust to this news. These initial feelings can often be 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 aren't sure how others will react. These feelings generally subside over time and you should not feel guilty about the way you are feeling.

Most importantly, remember that your child's limb difference is just a small part of who he or she is or will be. Limb difference does not have to prevent your child from achieving the personal goals, independence and aspirations he or she will strive for in life.

If your child was born with a limb difference he or she will naturally develop ways to learn new tasks. This is not to say that your child may, at times, feel different from their peers. At times your son or daughter may feel sad, frustrated or annoyed that they are missing all or part of a limb. As your child grows you will also find that you engage in more joint decisions regarding prosthetics and treatment together.

Throughout your child's life, and particularly as they move through key developmental stages, it is valuable to talk about how you all feel. It is best to encourage your child to ask questions and discuss matters openly when you can.

Sharing news about your baby

Determining when, how and with whom to share information about your child's limb difference is a very personal decision. Some parents, who are aware they are having a child with a limb difference, choose to tell others prior to their baby's birth while others choose to wait until the baby arrives. Parents that learn about their child's limb difference following the birth may also delay telling others, often until they feel they are ready and have adequate information to share.

There is no right or wrong way to share your news; everyone is different and you are the best person to determine when and how you will tell others that your child has a limb difference.

Talking about a child's limb difference can be difficult for some families. It can also be tiring as you may be sharing the same information repetitively. You may also find that you receive a wide range of reactions from people, whether they are persons close to you or professionals, and it is best to be prepared for this. Reactions may range from being very positive to ones that are unsympathetic or insensitive.

As a parent you are likely to know a lot more about your child than anyone else. You are likely to have sought considerable information and conducted a lot of research regarding your child's limb difference. You are the best person to educate others about your child, even if it may be tiring and frustrating at times.

Your new baby

When your baby is born take time to marvel at him or her and spend time bonding. Nine months of eager expectation has arrived and you should enjoy spending time with your new and precious child.

You are likely to face all the challenges and experiences common to all new parents. Try and look after your health and wellbeing during this time of adjustment.

As the parent of a baby born with a limb difference you may experience some additional challenges and adjustments. In the first few weeks you will start to meet a variety of medical and allied health care professionals who are there to support your child and your family.

You may also be starting to make medical appointments (inside and outside of the hospital). As many parents experience some sleep deprivation or changes to sleeping patterns when a new baby arrives, it's a good idea to keep a notebook and folder handy to record appointment details.

You might also start hearing professionals using new words and terminology around you. Remember, don't hesitate to ask questions if anyone uses words or terms that you do not understand.

Accessing support

Introducing and talking about your new baby can be very comforting and is 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