

Fact Sheet

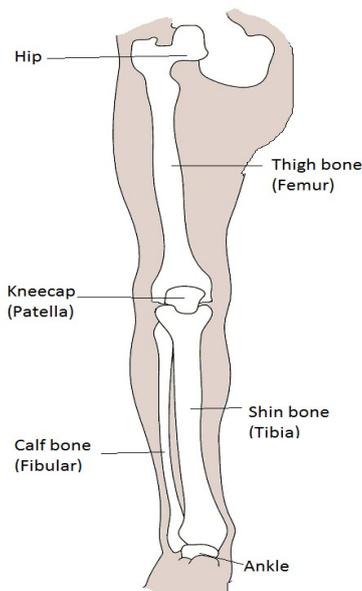


Leg Length Difference

What is a Leg Length Difference?

Finding out antenatally or after the birth of your baby, about a congenital (present at birth) condition which is likely to cause a leg length difference is distressing and worrying. This will be a time full of questions and this series of factsheets aims to answer some of those questions and to reassure you that you are not alone: support and information are available, from Steps and other sources.

There are three main long bones in the leg: the longest is the femur (thigh bone); of the two bones in the lower leg, the thicker one is the tibia and the thinner one is the fibula.



Lower limb deficiency, leading to leg length difference, can arise due to a range of conditions where the bones in the leg are shortened, incorrectly formed or absent at birth.

Diagnosis

Many cases are picked up at routine antenatal scans, around 12 or 20 weeks of pregnancy, when the femur length is measured and other limb abnormalities can be visually checked for. Other cases do not show until soon after birth or even later, when a child is learning to walk.

Reactions

Following a diagnosis or the indication of a problem, it is normal to feel shock, sadness and even anger. Your expectations of parenthood are starting to change and in some ways, you may feel grief for the baby you thought you were having. It's important to take time to think, to absorb the news and to accept your new circumstances.

Initial concerns may diminish as you start to learn more about your child's condition. You'll learn about the others who have trodden the same path before you with their inspiring and, above all, normal children - they're children who achieve their full potential and thrive in their own lives, as they grow and develop into adulthood.

Your fears about the reactions of friends and family will fade as the day-to-day practicality of having a new-born take over. Soon you'll accept that while your child's leg difference will inevitably play a role in their childhood, it is just a small part of who he or she is and will grow up to be.

Why does it happen?

In most cases conditions that cause a leg length difference, the cause is unknown. Some conditions can, occasionally, be passed on in families and is sometimes can be

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associated with other conditions and syndromes (although in most cases, a cause is simply not known). A thorough examination and diagnostic tests will detect the presence or absence of other such conditions.

Treatment

Treatment depends on the condition and exact form and severity. Consultants will assess each child individually and work with your family to decide on the best option for your child.

Further investigations such as x-rays and MRI following birth may be used to guide treatment, such as options around reconstruction and would depend on many factors.

Sharing the news

When and how you tell close family, friends and other relatives about your child's condition is a very personal decision. If you were aware of the condition during the pregnancy, you may feel ready to discuss it with some of them before the birth - or you may prefer to wait until you know more about potential treatments and prognosis before feeling ready to share it with other people. Likewise, if you only become aware of a problem following your baby's birth, you may want to delay telling others until you've had time to adjust to the situation and inform yourself about your family's options.

Steps provides a Family Contact Service, which will put you in touch with another family which has been in a similar situation. Alternatively, if you don't feel ready to talk to a stranger, the Steps closed Facebook group or public page are excellent sources of family stories and provide a secure environment in which to ask questions of those who have experienced similar situations.

You are likely to have already researched your child's condition extensively and will almost certainly know a lot more about their prognosis than anyone in your circle. This means you're probably the best person to inform friends/relatives about your child, even if you find constantly repeating yourself frustrating.

Life with your new baby

Following the birth of your baby and once the initial shock of diagnosis has started to wane, you will be faced with the

same rituals as all new parents: sleepless nights, nappies and feeding will take up every available waking hour (including those when you'd otherwise be sleeping!). Take time to get to know your little one, bond with them and accept them for the amazing and beautiful gift they are.

You'll be starting to arrange medical appointments, both routine and those associated with your child's condition. Take a relative or friend with you, as an extra pair of ears, and bring a note book, so you can record any information and refer to it when you need to.

It's also a helpful to write down any questions you may have beforehand - as sleep deprivation and exhaustion begin to kick in, your ability to remember everything will be impaired. Try to make notes of any new terminology you may hear and don't be afraid to ask questions if you come across something you don't understand.

How will it affect my child?

The emotional and physical effects of living with - and having treatment for - a leg length difference will vary with the type of treatment, from child to child and family to family. As the many achievements of the children whose families we have supported demonstrate, it is no barrier to success and the most important thing is to always encourage full participation in whatever your child shows an interest in.

Sources of support

Our helpline (01925 750271) is open from 9am until 5pm weekdays, for any questions you may have. Medical enquiries to be passed to our panel of NHS consultants. Email info@steps-charity.org.uk with a specific request or fill in a contact form on our website. The Steps closed Facebook Group is a friendly, safe way of discussing worries, sharing tips and finding emotional support.

Other Steps fact sheets are available on the website, focussing on the specific conditions relating to leg length difference.

Our Family Contact service identifies someone else who has been through similar and who's happy to talk about their experiences, on a one-to-one basis, to offer support and encouragement. For families also affected by limb difference of the arms reach.org.uk are very helpful.

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