# Tibial Hemimelia Fact Sheet

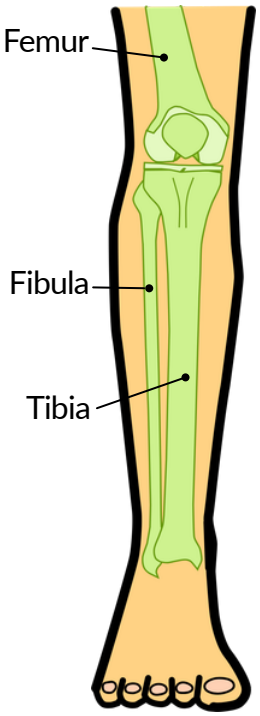
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Steps is the leading charity working for all those whose lives are affected by childhood lower limb conditions

## What is tibial hemimelia?




**Healthy Bones of the Leg**

There are two long bones in the lower leg: the thicker one is called the tibia and the thinner one is the fibula.

Tibial hemimelia is an extremely rare condition where a child is born with a partially or completely missing tibia.

It occurs either in one leg (unilateral) or, in around a third of cases, both legs (bilateral). In cases of unilateral tibial hemimelia, the condition most commonly affects the right leg.

There may be additional differences such as:

- The lower leg is short
- A foot or ankle abnormality
- The foot may have additional or absent toes
- The fibula may be abnormal
- The foot may be turned inward and the toes point downward (similar to clubfoot, but in tibial hemimelia this is due to the shortened tibia in relation to the fibula bone)
- The knee may be unstable, due to absent or underdeveloped knee ligaments and thigh muscles

A leg affected by tibial hemimelia can look different to an unaffected leg, but some parents report that it is not always obvious to other people.

## Why does it happen?

Tibial hemimelia happens early in pregnancy when a baby's limbs are forming, it is not linked to anything a parent has done during pregnancy and in most cases the cause is not known.

The condition effects 1 in every 1 million births. It can sometimes be passed on in families due to a genetic link and can be associated with other conditions, congenital deformities and syndromes.

Children and their family will be supported by a dedicated multidisciplinary team with expert knowledge in the treatment of the condition.

## Diagnosis

Sometimes tibial hemimelia can be detected on ultrasound scans from 16 weeks of pregnancy, but not all cases are picked up at this stage.

Some cases are not seen on ultrasound scan and may only become apparent after the baby is born, when the shorter leg becomes more noticeable.

When a child is diagnosed with tibial hemimelia a family may feel overwhelmed. However, orthopaedic specialist assessment and appropriate investigation provides clear treatment pathways to enable a child to lead a full and active life.

Steps have produced a downloadable publication, "Leg Length Difference Factsheet", about congenital lower limb length difference for expectant or new parents who have been told of a possible problem with their baby's leg(s).

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The Leading Charity for Lower Limb Conditions

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## Treatment

Treatment for every child is planned on an individual basis and is influenced by the severity of the condition; how much of the tibia is present, how much of the ankle has formed and the condition and stability of the foot, ankle and knee.

Investigations such as X-ray, ultrasound scan and MRI are used to classify the type of tibial hemimelia and determine whether the knee, thigh muscles and ankle are deficient.

**The two main surgical treatment approaches are:**

1. Limb reconstruction

This treatment aims to save the limb and enable the child to achieve the best functional outcome. Treatment may include multiple surgeries over a prolonged period and requires a high level of commitment from the family. This may include improving the position of the ankle and stability of the knee (joint stabilisation) or using an external frame which is applied to the leg to lengthen the tibia over a number of months (limb lengthening).

2. Amputation

If the tibia is absent and the knee joint is not functional, there may be no option for surgical rebuilding (limb reconstruction) and amputation may be the safest treatment. Children are fitted with a prosthetic limb and can function very well, living an active and fulfilling life.

## When will treatment start?

The timing of treatment will depend on the treatment pathway, which again will be dictated by the severity of the condition. In mild cases, with a reasonably functioning ankle, a shoe raise can be used as your child begins to walk until leg lengthening and correction of the ankle is attempted. Some mild cases may be managed by a shoe raise alone, without surgery. If amputation is the best option, this is usually performed when the child is around one year old.

## How will this affect my child?

The emotional and physical effects of living with and having treatment for tibial hemimelia will vary with the type of treatment, from child to child and family to family.

Discussing your child's condition and treatment with them openly will help them prepare for whatever the future holds.

As the many achievements of the children whose families we have supported demonstrate, the condition is not a barrier to achievement and the most important thing is to always encourage full participation in whatever your child shows an interest in.

Access to new technologies and advanced prostheses means that your child should be able to participate fully in almost any activity.

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## Support

## Steps is here to help

**Contact Steps:** +44 (0) 1925 750271 to answer any practical questions you have.

**Email:** info@steps-charity.org.uk with questions.

**Family Contact Service:** If you want to talk to someone who has been through a similar situation, one on one.

**Facebook Group:** A closed group where you can talk about your worries, share helpful tips, and find emotional support.

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