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



# Fact Sheet



# Leg Lengthening Nails

#### What is a lengthening nail and what is it used for?

A rod or lengthening 'nail' is an expandable telescopic rod that fits in the hollow canal inside the bone to be lengthened. It may be referred to as an 'intramedullary nail'. The phrase 'intramedullary' means 'inside the bone'. The rod or nail is controlled by a remote control outside the body. This lengthens the rod and gently grows new bone. Your doctor will assess if this procedure is suitable for your child. This procedure is not recommended for children with small bones and open growth plates.

The lengthening rod or nail is used to help lengthen the leg of someone who has a short leg. This is usually caused by a condition a child has been born with, which has led to one leg not growing as well as it should. Each child's needs are unique and lengthening nails will only be considered if a child's bone is large enough and the growth plates have fused. A PRECICE® nail may be inserted in a child's thigh bone (femur) starting at about age eight years. For the shin bone (tibia), it is preferable to wait until close to skeletal maturity which is usually around the age of 14 years in girls and 16 years in boys; the age will vary depending on the condition and the bones. The doctor will measure the length of the bone on an X-ray to see if it is long enough to accommodate the nail.

#### What type of nails or rods are available?

There are different types of intramedullary lengthening nail, but the most common one, used by surgeons in the UK, is called the PRECICE®. A device known as the 'FitBone' is also starting to be used in the UK but is not yet widely available. There are other lengthening nails throughout the world and this technology is still advancing.

# How is it fitted?

An incision (cut) is made through the skin into the bone, making space for the nail. The nail sits inside the bone, where the new bone growth happens. The intermedullary nail is fitted under general anaesthetic, meaning your child will sleep through the surgery. A controlled cut in the bone, called an osteotomy, creates a site where the new bone can form. The whole operation takes around three hours but may vary depending on individual circumstances. The nail is secured with small screws and operated by a remote control. The wounds from surgery are closed with stitches.

# How long does it take to lengthen the leg?

After surgery, the consultant will wait for five to seven days and then start the lengthening process. Lengthening is usually around 1mm per day, however, if the joint stiffness or contractures set in (a shortening and hardening of the muscles) – the lengthening process will be slowed or paused, so the time taken to grow the bone is increased. An average of 45 days per cm of growth is often suggested: this does not mean your child will need to stay in hospital for this length of time.

Once the desired length is achieved, the bone is left to heal and harden. After lengthening, the leg will more than likely remain weak for some time. Strengthening exercises increase gradually once full weight-bearing is to be allowed. It can take up to 1 year to recover from a considerable amount of lengthening.



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For the first few weeks, your child may need help washing, dressing, and getting around; a wheelchair may help reduce reliance on crutches, but growing new bone uses a lot of energy and your child may seem more tired than normal. If your child's tiredness seems excessive, contact your hospital to make sure there is nothing else causing this. In the first few days there may be some swelling or redness; should a scab form this is good as it is one way of showing the body is protecting itself. It is also normal for your child to feel tingling or itchiness; a pulling feeling around the wound closure and, as new tissue grows, a slight lumpy feeling. If your child becomes bored or unable to do much, it may be advisable to arrange activities with friends at home, such as craft, film, and homework days. They will help to keep your child connected with their classmates and education.

#### How do we prepare for coming home?

Depending on the personal care required, it may be possible for your child to attend school normally following their surgery. If a child is to attend school during the leg lengthening process, a parent or carer will need to attend school to activate the nail, probably during the lunchtime break. Some absence from school is expected and careful planning of schoolwork with your child's teacher will minimise disruption to your child's education. Your child maybe absent from school for up to 6 weeks, in this instance your school may be able to provide a tutor. It is advisable to discuss all options with your school to see how best they can support you and your child.

# What are the risks of surgery?

All surgeries involve some risk, such as scarring, bleeding or infection, but your medical team is trained to deal with complications. Small increases in bone length are well tolerated, but, as the amount to be lengthened increases, so too do the complications of stiffness and potential damage to the nearby joints.

#### What happens when the bone has grown enough?

Once your medical team have decided that the bone has grown enough, lengthening is stopped. Sometimes, the desired length is less than planned because of

# We don't take walking for granted

complications such as pain and stiffness. If the difference is small, (less than 2 cm) then an insole inside the shoe may help to correct this difference. Most, if not all, centres these days routinely remove the nail as it has an internal mechanism and there is a small uncertainty of the long-term effects on the individual if not removed: bearing in mind every child's treatment will be different and it will always be best to speak to your surgeon to decide which is the best course of action for your child. If, for any reason, there may be a future need to correct the bone with surgery then plans should be discussed with your surgeon going forward.

### What is the long-term outcome?

Once the bone has healed, your child should be able to continue with all their regular activities. The bones in your child's body are constantly growing and the bone formed during the lengthening process will be as strong as 'naturally' formed bone. Follow-up appointments are usual until 'skeletal maturity' at 12-15 years old, in order to ensure that the aims of treatment have been achieved.

#### Sources of support

Our helpline +44 (0) 1925 750271 is open from 9am until 5pm on weekdays, for any questions you may have about practical support. Medical enquiries can 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 and safe way of discussing your worries, sharing tips and finding emotional support. Our Family Contact service identifies someone else who has been through a similar situation and who's happy to talk about their experiences, on a one-to-one basis, to offer support.

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