

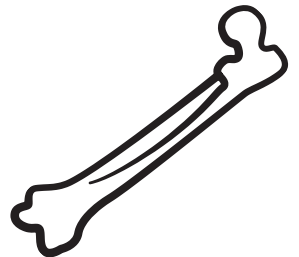
# Intramedullary rodding surgery for children with Osteogenesis Imperfecta (OI)

Information for families



**NHS**

Great Ormond Street  
Hospital for Children  
NHS Foundation Trust



# This information sheet from Great Ormond Street Hospital (GOSH) explains about rodding surgery in osteogenesis imperfecta and what to expect when your child comes to GOSH for assessment and treatment.

## Introduction

Children and young people with Osteogenesis Imperfecta (OI) are more likely to develop fractures and bony changes such as bowing (bending) and shortening.

Rodding surgery may be suggested or recommended by your child's medical team. Rodding surgery involves an operation to insert a straight metal rod, made of stainless steel, lengthwise into the middle section of the bone, known as the intramedullary canal.

Rodding is usually carried out to the long bones of arms and legs, most commonly the thigh bone (femur) and shin bone (tibia).

The aims of intramedullary rodding surgery are:

- To treat an acute fracture
- To treat a bone which has recurrent fractures making it weaker and/or changing its shape
- To re-align bones which are bowed or misshapen in order to reduce risk of fracture and/or improve movement and function

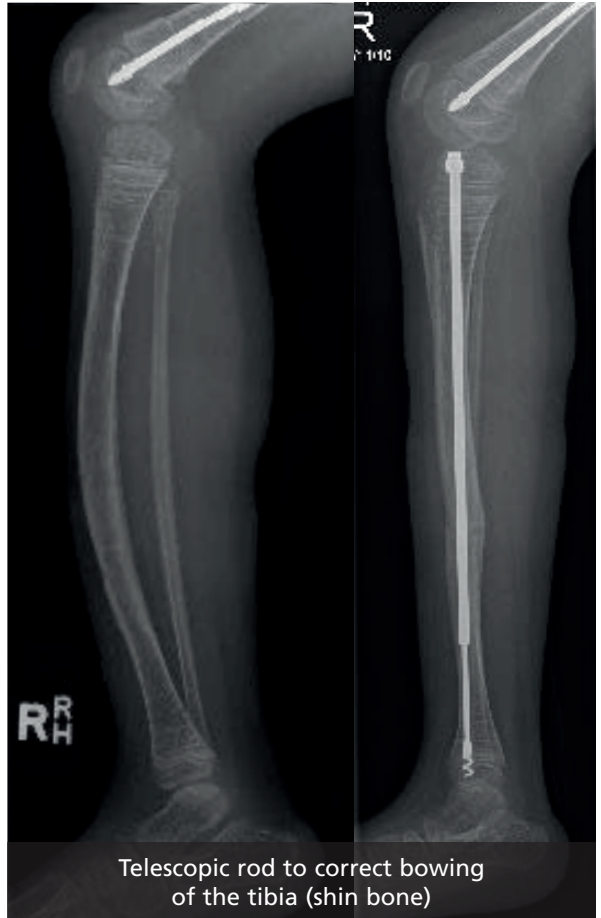
In OI, intramedullary rods may make the bones stronger but they do not completely take away the risk of having fractures to those bones.

## Types of rods

There are two main types of intramedullary rods:

### Telescopic rods (also known as growing rods)

Telescopic rods are placed within the intramedullary canal and are anchored at the top and lower end of the bones. Telescopic rods lengthen as the child grows.



Telescopic rod to correct bowing of the tibia (shin bone)

## Non-telescopic rods

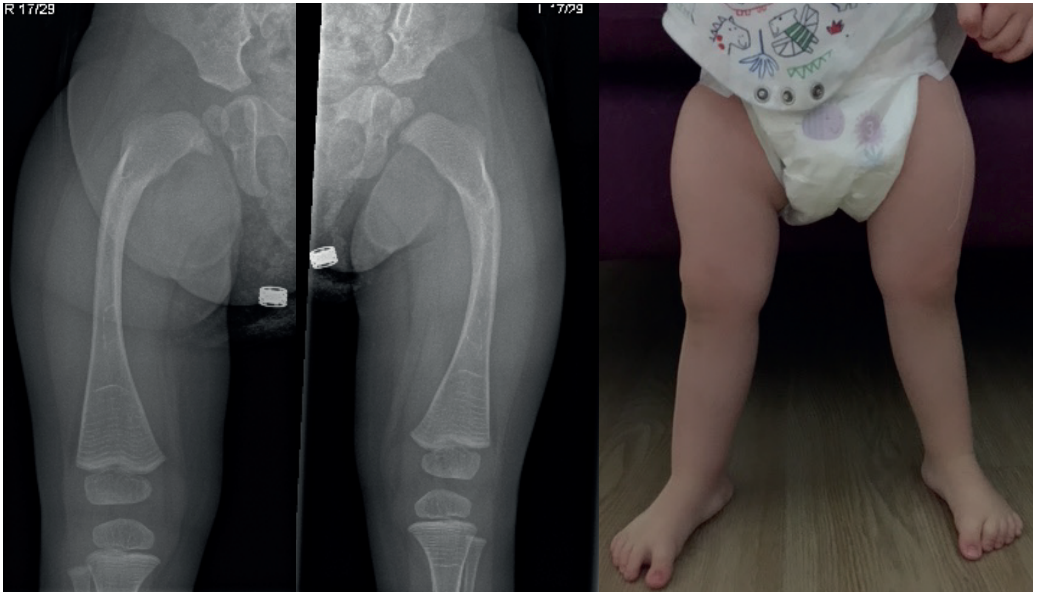
Non-telescopic rods are a fixed length and do not lengthen as the bone grows, so eventually there may be un-rodged bone at the bottom. One type of non-telescopic rod used is called a 'Rush pin'.

As your child grows, rods may need changing to bigger sizes. Due to their lengthening mechanisms, telescopic rods tend to last longer but eventually also need replacing.

Which type of rod used depends on several factors including the complexity of the surgery, the size of the bone, and the age and growth rate of your child.

Your child may have more than one rod inserted at the same time if indicated – for example, if both thigh bones are bowed, a rod might be inserted into each leg.

In some cases, additional metalwork (plates and screws) may be needed to further stabilise a rod or to treat a complex fracture.



A 2 year old child with severe OI starting to take weight through his legs and wanting to start walking – rodding surgery has been advised to correct the bowing of his femora (thigh bones).



Non-telescopic rod used to treat a fracture of the femur (thigh bone)



Telescopic growing rod in a tibia (shin bone)

### **Osteotomies**

When the bones are significantly bowed or misshapen, an osteotomy may be needed. This involves surgically breaking the bone to straighten and re-align it, enabling the insertion of the intramedullary rod. In some cases more than one osteotomy is needed. Osteotomies may also be needed when an existing rod is being replaced.

### **Incisions/scars**

Surgical incisions and the resulting scars are variable and depend on the complexity of the surgery and type of rod used. At times, more than one incision is needed.

### **Bisphosphonates**

If your child is on bisphosphonates, changes to their treatment programme may be indicated before and after rodding surgery. Please inform your child's orthopaedic surgeon if your child is on bisphosphonate therapy.

# Hospital admission and after-care

## Pre-operative assessment

If your child's orthopaedic surgeon recommends elective rodding surgery, appropriate planning is advisable. Your child may be invited into hospital for a pre-operative assessment and give you an opportunity to discuss the surgery in more detail. Your child may also be assessed by an Occupational Therapist and/or Physiotherapist who will ensure your child has access to the appropriate equipment and support after their surgery.

## Plaster casts and weight-bearing

After surgery, your child may need a plaster cast to protect the rodded bone and help healing by keeping the limb still and well-aligned. Casts are often applied in theatre immediately after the surgery, but may need completing or modifying later.

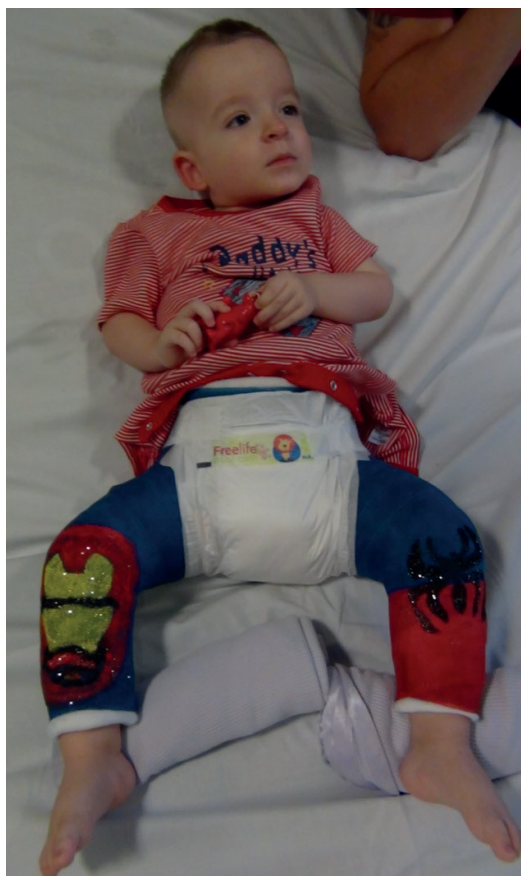
The type of cast depends on which bone has been rodded. Although the orthopaedic team try to plan ahead, occasionally the final decision whether to cast or not and the type of cast needed, will be made after surgery by your child's surgeon.

Sometimes your child will not be allowed to put pressure or weight through their operated limb. You and your child will be given specific post-operative instructions regarding weight-bearing restrictions and length of time spent in a plaster.



Bilateral long-leg plaster casts after tibial rodding surgery





Child in hip spica cast following bilateral femoral rodding – hip spica casts immobilise the hips and come up to the waist meaning sitting upright can be difficult





A child following bilateral tibial rodding showing straightening of the shin bones



### Ward admission

After the surgery, your child will be admitted to the ward where they will stay until their pain is well controlled, they are medically stable, and are able to move safely and comfortably. This can vary, usually anything between one to two days to a week.

If needed, your child will be seen by an Occupational Therapist and/or Physiotherapist on the ward to help your child move safely, start their rehabilitation, and ensure it is safe and appropriate for them to go home. If needed, equipment such as wheelchairs and walking aids will be loaned out to your child.

Please note that your child may not need to have more X-rays done on the ward as images will have been taken in theatre.

### Follow-up

A few weeks after discharge, your child will be followed up in an orthopaedic outpatient clinic. Your child will have X-rays to monitor the position of the rod and assess healing. Changes to, or removal of, plaster casts may occur at this appointment. Your child will have their wounds checked and the movement in their operated limb will be assessed. You may be seen by a physiotherapist and advice regarding rehabilitation will be given.

Future follow-up appointments will be arranged if needed.

# Rehabilitation

Your child may experience joint stiffness, muscle weakness and reduced mobility after rodding surgery. It is important to start moving as soon as it is safe to do so, and in some instances if advised, early weight-bearing through an operated limb will aid the healing process.

Physiotherapy and Occupational Therapy input may be needed to help your child to improve their mobility and promote regain their independence at home and/or school. Referrals to local therapy services near your home may be organised to assist this.

If your child has had rodding to re-align bones with severe bowing, they may now be able to start standing and walking. They will need graded rehabilitation and may need walking aids to achieve this; this will be guided by your child's physiotherapist.

Your child may be offered hydrotherapy (exercising in water), an excellent way to start gentle rehabilitation. Surgical wounds need to be healed prior to hydrotherapy.

In some cases, specialist orthotics, for example insoles and splints are needed to promote good alignment or to protect the rodded bone.



Child having physiotherapy post rodding surgery



## Return to school

We encourage returning to school as soon as your child is comfortable and it is safe to do so. Risk assessments and liaison with the school may be required to achieve this; this is something that can be discussed with your child's local therapy team, or the team at GOSH.

In some instances it may be too difficult for your child to attend school, for example if they are in a large plaster such as hip spica, or if your child's school is not accessible enough. Your child's school may be able to provide home-based work and tuition if your child is off school for a prolonged period.

## Potential complications

- As with any surgery, there are risks associated with a general anaesthetic, as well as complications involving bleeding, pain and infection – these risks will be discussed in more detail by your child's surgeon before the operation.
- Rods will need replacing as your child grows – this will require surgery and a period of recovery each time. If your child has rodding surgery at a young age, they will most likely require several repeat surgeries.
- Occasionally osteotomies can take longer to heal – this may lead to longer periods spent in plaster and/or changes to your child's bisphosphonate treatment.
- At times, the intramedullary rods loosen and displace – this can lead to pain and loss of movement. Rarely, the lengthening mechanism of telescopic rods fails to work. In both cases, your child's rod will need to be revised or replaced.
- Intramedullary rods can bend with sufficient force or trauma – if your child's rod is bent it may need to be replaced.
- Your child's leg length may change following rodding surgery – in some cases shoe raises are indicated. Orthopaedic intervention may be needed if this difference is significant or impacts on function.

To discuss your child's rodding surgery, please contact your child's Orthopaedic Team or the Osteogenesis Imperfecta Team at Great Ormond Street Hospital.

## Contact Details

Highly Specialised Childhood Complex  
Osteogenesis Imperfecta Service  
020 7405 9200 ext 5293

## Additional Resources

Please visit [www.steps-charity.org.uk](http://www.steps-charity.org.uk) for practical information about Hip Spica Casts



*"Rodding was the hardest but also the best decision we made for Lincoln. We now have peace of mind that the extra support to his bones will help our cheeky, adventurous little boy achieve anything he wants!! The world is now his oyster!!"*



**NHS**

**Great Ormond Street  
Hospital for Children**

NHS Foundation Trust

# **Intramedullary rodding surgery for children with Osteogenesis Imperfecta (OI)**

## Information for families

This information sheet from Great Ormond Street Hospital (GOSH) explains about rodding surgery in osteogenesis and what to expect when your child comes to GOSH for assessment and treatment.

© GOSH NHS Foundation Trust April 2020

Ref: 2020F2106

Compiled by the Osteogenesis Imperfecta Team  
in collaboration with the Child and Family Information Group.

Great Ormond Street Hospital for Children NHS Foundation Trust  
Great Ormond Street  
London WC1N 3JH

[www.gosh.nhs.uk](http://www.gosh.nhs.uk)