



A Patient's guide to

Lower limb lengthening with a Precice Nail

Introduction

You have been given this booklet because it has been suggested that you have treatment with a Precice lengthening nail. It has been designed to provide you with general information about how the device works as well as how it will impact on your life. We hope it helps to answer some of your questions. If it does not, please do not hesitate to contact us. There is a list of contact numbers on page 20 of this booklet.

Your participation is essential to the success of your treatment. You will need to manage the adjustment of the nail at home. In order to prevent complications and maintain mobility and movement in your joints it is essential that you perform any exercises suggested by the physiotherapists.

What is a Precice Nail?

A Precice nail is a device, surgically placed within the bone, which is used to grow new bone and change the length of the limb (fig 1). The nail contains a magnet and a gear system, this enables the nail to lengthen or shorten. It is activated when a programmed external handset is placed on the limb (fig. 2).



The operation

The operation involves the nail being inserted into the centre of your bone and secured with screws. Your bone is also divided in a specific place. You will have surgical wounds where the nail and screws are inserted and also in the area where the bone has been divided.

Figure 1: Precice nail and divided bone.

The lengthening process

You will normally start to lengthen your nail 6-7 days after your operation. Individual instructions will be given on how to use the handset and other equipment and you will be supported until you are confident and feel competent to carry out the adjustments independently. The handset is normally used 3 times per day. It needs to be placed in a specific place on your limb for the device to work. Your surgeon will advise you or mark where this is.



The handset contains a strong magnet. Please be aware that when the handset is turned on, the strong magnet is activated. Metal objects, watches, mobile phones and credit cards should not be placed near the device. Family members or carers with a heart pacemaker should not be present when the device is turned on.

Figure 2: The handset applied to the skin.

After a week, the division in the bone will be in the early stages of healing, as the bone is pulled apart using the nail, new bone starts to form along a line of tension created by the device and then continues to grow in the gap. (fig. 3). This is a slow process.



As your bone is lengthened, your soft tissues also get stretched. **Muscles become very tight and it is of prime importance to maintain movement in the hips, knees and ankles.** You will find that they will become stiff, in severe cases this can become permanent. The physiotherapists will provide you with exercises to help prevent this.

Figure 3. New bone growth

The nerves in your limb are also stretched as the limb is lengthened. If you notice a change in sensation, get pins and needles or numbness it is important that you contact a member of the limb reconstruction team. Contact numbers are on page 20 of this booklet.

How long does it take?

Your surgeon will be able to give you the approximate time you can expect to have the nail in place but it will most likely be for 18-24 months. Bone is normally lengthened at a rate of 1mm/day. The bone then needs to harden (consolidate) before the nail is removed.

For example, a 50mm (5cm) lengthening will take 50 days until you finish the lengthening process. During this time you will not be able to bear weight on it. It is, however, important to maintain your range of movement with exercises.

Every person is different, and the amount of time it takes to lengthen your bone may be different from this. You may need to attend clinic every 2 weeks whilst you are lengthening. During this visit you will have x-rays to check how well the new bone is forming. Based on these x-rays or other symptoms we may slow down or speed up the rate at which we adjust the nail.

Living with a Precise Nail

Pain

You may already be experiencing pain for which you are taking medication. Please inform nursing and medical staff about these and how effective they have been.

Immediately following surgery you may either have an epidural, or patient controlled analgesia (PCA). The PCA enables you to press a button to feed pain relieving drugs straight into your blood system. Once the initial pain has eased this will be changed to pain killing tablets. On discharge you will be given a week's supply. These should be renewed via your GP. Do ensure your new supply of medication is ordered before the supply given by the hospital runs out.

At home you may experience pain during the lengthening process as the bone stretches alongside the nerves, muscles and blood vessels. This can be relieved with the appropriate medication or adjustments to the rate at which we lengthen, so please do inform us if your symptoms change or pain is not well controlled.

There are some pain killers that you should avoid as they are thought to interfere with the process of bone healing. These are aspirin and Non Steroidal Anti-inflammatory Drugs (NSAIDS).

NSAIDS include Diclofenac, Ibuprofen, Ketoprofen, Naproxen, Flurbiprofen, Indomethacin, Mefenamic Acid, Piroxicam. Please note that this is not an exclusive list and that these are generic names and commercial names may be different. Ask your chemist / nurse / GP for help if you are unsure.

MRI Scanning

The Precice nail is not MRI compatible and you must not have a MRI scan whilst you have a Precice Nail. Please ensure that you inform all medical staff and radiographers that you had this treatment.

Care of your surgical wound

Surgical wounds go through several stages of healing.

- Day 1-5: Inflammation, some swelling, reddening, clear non-smelly discharge and slight pain
- Day 5-14: Formation of scab - a protective covering over the wound
- Day 14 onwards: Strengthening and flattening of scar tissue

It is normal to have:

- Tingling or itching
- Slight lumpy feeling as new tissue forms
- Bruising around the wound
- A pulling feeling around your wound closure

Your wound may be closed using Steri-strips, absorbable stitches or non-absorbable stitches.

Non-absorbable stitches will need to be removed by your GP's practice nurse or district nurse 10-14 days after surgery.

You will have a dressing on your wounds after surgery. This can stay in place for a week if there are no concerns about infection. Once the wound is dry it can be left open to the air. It is important to wash your hands with soap and water and dry them on a clean towel before touching your wound or dressing.

Common emotional problems

Going into hospital is stressful and it is not unusual for patients undergoing prolonged treatment to experience varying degrees of emotional turmoil. Having limb lengthening may be the culmination of many years of treatment and there will be times when you feel it will never end. Reduced mobility will curtail your social life and you will be more dependent on others for your daily needs.

Not everyone suffers emotional problems but you should be aware that they can occur, and seek advice from your nurse or doctor if you feel you need extra support.

Diet

Although you may feel less hungry, it is important to eat well. Make sure you include at least one of the ingredients listed below in each meal to help bone and wound healing.

- Protein (found in meat, fish, cheese, eggs and milk)
- Calcium (milk, cheese, cereals and green vegetables)
- Vitamin C (fruit, fruit juices and green vegetables)
- Vitamin D (margarine, fish and fish liver oils)

Please be aware that some painkillers and restricted mobility can cause constipation. In order to relieve the symptoms of constipation try to drink plenty of water and eat food that contains fibre such as wholemeal cereal, wholemeal bread, fruit and vegetables.

Work and benefits

You may be able to return to work during the lengthening, it very much depends on what your job entails. Explain your situation to your employer and check whether they can make special arrangements if you need them. We are happy to help if your employer would like more information. A 'Fit Note' can also be completed by your surgeon stating any special requirements such as the need to keep your limb elevated, or attend regular physiotherapy sessions.

If you are unable to work you may be entitled to claim benefit. Contact your local Citizens Advice Bureau for information, or speak to the Disability Employment Advisor at your local Job Centre.

Leisure time – sport and holidays

Your consultant will advise you on when you will be able to go back to playing sport. Swimming is generally permitted at an early stage of treatment, but always check first.

We advise you not to travel too far from home during the lengthening process; if you want to go away on holiday you should discuss it with your consultant. If you need to travel by aeroplane you will need to explain your situation to the airline.

Scar tissue, either during or following treatment should always be protected from the sun using sun-block.

Complications

Deep Vein Thrombosis (DVT)

There is a risk of developing a DVT. This is a blood clot which is treated by medication that thins the blood. Your risk factors for this occurring will be assessed by medical staff and if necessary you be placed on anticoagulation therapy.

Infection

The following may be signs of an infection in your surgical wound. If these are present contact your GP as soon as possible

- Increased pain in the area
- Spreading redness of the skin
- Increased discharge or pus
- Increased swelling
- You have a temperature or feel unwell.
- The wound is not healing

If you were to get an infection within the bone, around the nail, the nail will need to be removed and you may require treatment using an external fixator.

Joint stiffness and soft tissue tightness

This can be a problem and may affect your ability to mobilise. It is of prime importance that you perform the exercises that the Physiotherapists provide, or wear any necessary splints as instructed. In severe cases, surgery may be required to release tightness in the soft tissues to allow a full range of movement.

Joint instability

Following long lengthening procedures there is a small risk of dislocation of the surrounding joint. This particularly applies to the hip and the knee when lengthening a femur and to the knee when lengthening a tibia. This is monitored during the lengthening process and whilst it can be prevented with aggressive physiotherapy, its occurrence may lead to abandoning further lengthening.

Nerve and blood vessel injury

Rarely nerves and blood vessels can become damaged. This can be either at the time of surgery or during the subsequent lengthening of the bone. You should inform nursing and/or medical staff if you experience pain, numbness or pins and needles. Should this occur during the lengthening process this may mean that we slow down the rate of adjustment or even stop lengthening. Usually, this wears off, but in some cases it may become permanent. It is important that you inform a member of the Limb Reconstruction Team should these symptoms occur.

Failure to gain length/delayed union

This may occur if the bone does not form during lengthening or takes a long time to mature. Other reasons for failure to gain length relate to problems with stretching the nerves, blood vessels, muscles and tendons. Your consultant will advise you about treatments should this arise.

Problems with the nail

The nail or screws holding it in place may become loose, or there may be a problem with the mechanism in the nail. Should this occur, further surgery such as replacing the nail or treatment with an external fixator may be required.

Refracture

Following removal of the nail, fractures are a rare problem. If this were to occur it would possibly require further surgery or a period in a cast or brace.

Can I be worse off?

The worst case scenario is that if there were an uncontrolled infection, damage to the arteries and nerves or interruption of the blood supply to the muscles, there is a risk that this could lead to amputation of the limb being necessary.

General Advice

Smoking

We strongly advise that you do not smoke or spend any time in a smoky environment. Smoking is known to delay bone healing and increase the risk of complications. There are many options available to help you quit. Your G.P will be able to give you advice or you can contact your local NHS Stop Smoking Services:

For advice, help and support:

Call **Smokefree National Helpline** on 0300 123 1044

Or go to www.nhs.uk/smokefree or www.facebook.com/nhssmokefree

Please be aware that the RNOH has adopted a site-wide no smoking policy. Patients or visitors are requested not to smoke or use electronic cigarettes (e-cigarettes) in the hospital buildings or grounds.

Contraception pill or Hormone Replacement Therapy (HRT)

Women will need to stop taking the pill or HRT six weeks before treatment. Your doctor will have discussed this with you. Care should be taken not to get pregnant and alternative forms of contraception should be used.

Allergies

Please advise nursing or medical staff if you have any allergies.

Medication

Please advise nursing or medical staff if you are taking any medication.

Location of services

All in-patient care takes place at the Stanmore site.

Out-patient visits may be either at the Stanmore site or in central London at Bolsover Street. It is important that you check the location of any clinic appointments.

Hospital stay

You are likely to be in hospital for approximately 1 week after the nail is inserted. During this time you will be taught how to use the apparatus. You will also receive physiotherapy. The exercises given to you by the physiotherapists are extremely important and will aid you to mobilise and help prevent complications associated with treatment. If appropriate, you may also be reviewed by the Occupational Therapist.

Coming into hospital

You will normally be admitted to the RNOH on the day of your operation. Unless otherwise instructed, you should attend the admission lounge, based in the Out-patient department at 7am. From here you will be allocated a bed / ward. Full details about coming in to hospital will be given by the admissions team and nurses at your pre-operative assessment clinic appointment.

Day of discharge

We will aim to discharge you from the ward before 11 am, so please ensure that your family member / carer is aware to collect you before this time.

The doctors will have told you when they wish to review you in clinic. The most common time is 2 weeks after the operation, although this can vary for individual patients. If it is possible to make you an appointment before you go home the nurses will inform you of the date, time and venue (your outpatient review may be at either Stanmore or Bolsover Street). If this is not possible an appointment will be sent to you at home. The outpatient review may take several hours as you will have x-rays and see the Surgeon.

The ward nurses will also arrange for any necessary nursing appointments (for example, removal of stitches to be done either by your district nurse or the nurse at your GP surgery).

Travel to hospital

Detailed maps of each hospital site as well as advice on public transport and parking can be found on the hospital website:

<http://www.rnoh.nhs.uk/home/how-find-us>

Car

If you are travelling by car, you may find it easier to sit in the front seat with the seat pushed back. Cushions can be used to support your leg.

You should not drive until the bone has healed. Applying pressure to the limb, such as when braking, may damage the mechanism of the nail. This may lead to failure of treatment and further surgery. You will need to discuss your return to driving with the DVLA and your insurance company.

Hospital Transport

When booking an appointment or an admission at the RNOH's Stanmore site or an appointment at the RNOH's Bolsover Street site, it is your responsibility to make your own way to and from the hospital. If you require transport for medical need only, you will need to contact the transport assessment team for a confidential assessment at least 48hrs before your appointment. You will be screened using a set of questions to establish your mobility and potential for specialist care on the journey.

Please call the transport assessment team:

Monday-Friday between 09.00 and 17.00 on 020 7510 4637

If you would like further details about the Patient Transport Assessment Scheme, please ask for a copy of:

"The patient's guide to the Patient Transport Assessment Scheme"

Your hospital details

Hospital number: _____

Consultant: _____

Ward & Ext.: _____

Nurse Specialist: _____

Physiotherapist: _____

Contact numbers

Hospital switchboard:	020 8954 2300
Outpatient appointments:	020 8909 5516
Limb reconstruction team secretary:	020 8909 5890
Clinical Nurse Specialist Limb Reconstruction:	020 8385 3012
Clinical Nurse Specialist Paediatrics:	020 8909 5409

The team can be also be contacted via email:
limbreconstruction@rnoh.nhs.uk

In the event that you are unable to contact a member of the limb reconstruction team and feel that you have an urgent problem, you should visit your GP or local emergency department for advice.

Please note that this is an advisory leaflet only. Your experiences may differ from those described.

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