



Royal Orthopaedic Hospital NHS Foundation Trust Patient Information

Hemi-Pelvic Endoprosthetic Replacement

Welcome to the Royal Orthopaedic Hospital (ROH).
For further information please visit www.roh.nhs.uk

Information and Advice

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Introduction

As part of the treatment for your bone tumour the Surgeons here at the Royal Orthopaedic Hospital may need to remove your diseased bone and replace it with a metal implant. This metal implant is called an **Endoprosthetic Replacement** (or an EPR). The EPR is made of titanium alloy and is the same shape and size as the bone that has been removed. The EPR usually includes one of your joints, depending on where your tumour is. This booklet is designed to give you and your family as much information as possible about the surgery, the EPR and your hospital stay. You will learn how to use and look after your new prosthesis, which will allow you to return to a good level of function. However you may need to make some changes to your lifestyle. We hope that you will find this booklet beneficial. If you do have any comments, please do not hesitate to let us know so that we can add them for the benefit of future patients. Our contact details are at the back of the booklet.

Before your operation

You will be admitted to one of the wards a few days before your operation. The Nurse will welcome you to the ward and complete the necessary paperwork required during your stay. It is important that the Doctor or Nurse knows about your medication, in particular if there has been any recent changes due to health reasons (e.g. if you are taking Warfarin). At this stage you may need a few further tests in preparation for your surgery such as a blood test or X-ray. You may also need to see the Anaesthetist, who will put you to sleep during your operation and they will discuss with you any worries or concerns about pain management following your surgery. You will be seen on one of the Consultants ward rounds. This is a good opportunity for you to ask any questions that you may have, although there are always members of the Bone Tumour Team available for you to talk to. Once you feel you understand what operation is to be performed you will be asked to sign a consent form.

The operation

On the day of your operation you will be unable to eat and may be given some "bowel preparation" prior to surgery. A Ward Nurse will escort you to theatre and transfer you to the care of the theatre staff. Once you have been put to sleep by the Anaesthetist, the Surgeons will remove the bone containing your tumour.

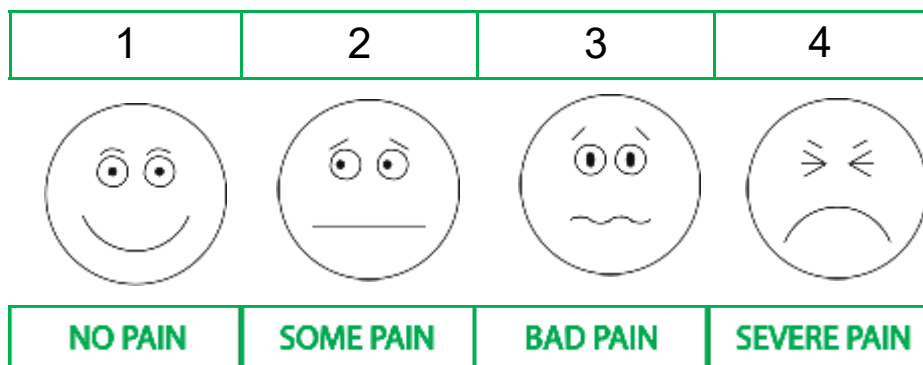
What happens during the operation?

- A cut will be made to get to the bone.
- Your biopsy scar will be removed at the same time.
- Some muscle and soft tissue may need to be removed with the bone.
- The prosthesis is then inserted and is fixed in place with bone cement.
- A drain is inserted which helps to remove blood and prevent swelling.
- The wound is closed with either dissolvable stitches or skin clips and an opsite dressing (a clear plastic film) which will cover the wound for two weeks.
- A pressure bandage (a soft bulky dressing) will be wrapped around your leg.
- You may spend the night in HDU (High Dependency Unit) where the nurses and doctors will ensure you have adequate pain relief and monitor your post-operative recovery.
- Close immediate family are able to visit you whilst in HDU.
- You will then be transferred back to your original ward.

Pain control

There are a number of methods of pain relief used. You will be connected to a machine that contains a supply of pain relieving medicine. There will be a tube leading from the pump either into a vein in your arm (IV) or a small tube into your back (Epidural). You will be given a button to press to tell the machine to give you a dose of painkiller. The pump will be programmed by your Doctor or Nurse to deliver a dose of regional nerve block, when you press the button. You will be given Paracetamol and sometimes an anti-inflammatory drug (such as Ibuprofen) as well as the pump. This combination of drugs will give you the best possible pain relief. Good pain relief means that you will be able to move about without much pain. Early movement will speed up your recovery and you may even be able to go home sooner. The Physiotherapist will help you to do this! If you have any questions about pain and pain control the Nurses on the ward, the Pain Sister and the Anaesthetist will be happy to talk to you.

To make sure that you do have good pain relief the nurse will ask you to describe your pain on a scale of 0 – 3:



Hemi-Pelvic Endoprosthetic Replacement

This EPR replaces the hip joint and a proportion of the pelvis (how much depends upon the extent of the tumour). The EPR is custom made for each individual and includes a joint similar to a total hip replacement. During the operation many muscles will have to be cut away from the bone that is being removed. These muscles will then be re-attached to each other wherever possible.

Post operative care

On the first or second post-operative day your pressure bandage will be removed. You will still be able to do your physiotherapy with the drain in place. The Nurses will remove your drain when drainage is at a minimum. You will be given anti-embolic stockings to reduce the risk of blood clots. You must wear these for up to 6 weeks post surgery.

What will the physiotherapy do?

- Advise you about how to move and rest your leg
- Advise you how to control any swelling in your leg
- Teach you how to exercise your leg safely
- Teach you how to get out of bed
- Teach you how to walk with your new EPR
- Show you the safest way to get in and out of your chair
- Teach you how to climb stairs and steps
- Advise you about returning to normal activities / sport / work

You will be guided by the Physiotherapist as to how much exercise to do and when. When you are resting your leg, you must keep the knee facing the ceiling whenever possible. Most patients begin to learn to walk with their new prosthesis after about 5 to 7 days bed rest following your operation. You will be shown how to use a zimmer frame and then elbow crutches to help you walk. The physiotherapy will guide your rehabilitation but you will be expected to do your own exercises. You will also need to practice walking on your own, once the physiotherapy feels that you are safe.

The Occupational Therapist will be available to discuss and advise you on any aids or adaptations that you may need to help you to dress and function independently when you go home. You should expect to stay in hospital for between 2-3 weeks, depending on your progress. The Physiotherapist and nurses will tell you how you are getting on so you can make plans for going home. The Physiotherapist will give you a date for your week of intensive rehabilitation, and a home exercise program. This is usually around six weeks after your operation. You will be advised to continue and progress your



independence as you feel able until you come back for physiotherapy. If your Physiotherapist thinks it is appropriate, they may refer you for further inpatient or outpatient treatment nearer to your home. We will contact your local Physiotherapist if you already have one. When you leave hospital the nursing staff will give you a discharge letter, any medicines you may need and an EPR advice card.

What will I be able to do when I go home?

- Walk with 2 crutches
- Go up and down the stairs safely
- Get on and off your chair by yourself
- Perform a home exercise programme

Things to avoid with an EPR

Certain positions are to be avoided after a pelvic EPR as they could cause dislocation of the hip joint:

- Don't bend the affected leg more than 90 degrees
- Don't sit in low chair
- Don't cross your legs
- Don't drive until you are advised to do so
- Don't bend down to put your socks on

Some things can cause the EPR to wear out or to loosen. You should try to avoid the activities below.



High impact activities such as jumping and running
Twisting on your EPR Any contact sports



Your Intensive Physiotherapy Week

- The main aim of this week is to improve your confidence and to maximise your function
- It is important to bring comfortable clothes to exercise in such as shorts or loose tracksuit bottoms
- You will also need to bring your swimming suite

What happens during the physiotherapy week?

Most people really enjoy their week of physiotherapy. It is quite tiring but very worthwhile!

- The Physiotherapist will assess you and plan a treatment program with you
- You will spend most of your day either in the hydrotherapy pool or the gym
- You will also have the opportunity to speak to the Doctors if you have any questions
- The Occupational Therapist is available to discuss any concerns you may have about managing at home

At the end of this week, you will be given a new set of home exercises and you may also be referred on for further local physiotherapy treatment if it is thought to be necessary.

Don't worry about the Hickman Line or a PICC (Peripheral Inserted Central Catheter) as these can be covered up for hydrotherapy

What can I expect after 6 months?

- You should be able to walk without walking aids although some people like to use a stick for longer distances.
- You should have enough movement in your hip to sit comfortably
- You should have a near normal walking pattern but you may have a slight limp
- You should achieve a good level of function
- You will be able to swim and cycle but high impact activities and contact sports should be avoided (this includes running and twisting)
- You will be able to drive a car (if you have a license!) but you must let your insurance company know about your EPR



In general, the maximum function will be achieved by about six to nine months following the operation but in people who are having a lot of chemotherapy it may take even longer to get maximum benefit.

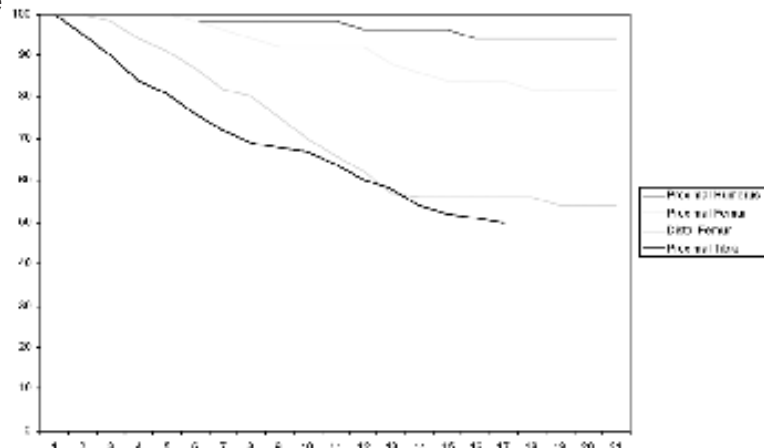


Regular exercise is the key to good function.

What can go wrong?

Loosening

This is probably the most common complication with the older prostheses but hopefully will be less of a problem with the modern ones. It takes place quite simply because the prosthesis shakes loose in the bone. It usually takes a considerable time to develop and some patients have had a prosthesis in for thirty years without any evidence of loosening. It usually starts to cause aching pain with activity, which gradually gets worse but sometimes may not cause any pain at all. This is one of the reasons why we will be X-raying your leg fairly frequently over the years simply to make sure the prosthesis is not working loose. If it does work loose it needs to be re-fixed in place. The decision when we do this depends partly on the symptoms an individual is getting and partly on X-ray appearances. It would be very unusual for us to recommend a revision to a new prosthesis unless your were getting significant discomfort.



Prosthesis problems

Very occasionally the prosthesis will break.

This is now very rare but can happen completely out of the blue. It is not usually painful but the leg simply gives way. If this happens the whole prosthesis will need to be revised.

Infection

Infection is the most significant complication that can develop. Because the EPR is made of foreign material, the body has difficulty combating any infection, which gets onto the surface of the EPR. Consequently any bacteria that are circulating in the body, which come into contact with the EPR can persist and cause various types of infection. Dental decay, gum disease and poor dental hygiene are risk factors for developing infection around the EPR. If you are having a root canal or dental extraction procedures you should have antibiotics prescribed for you.

You should also have antibiotics if you have any of the following:

- . Boils
- . Abscesses
- . In-growing toe nails
- . Acute infection
- . Any procedure where bleeding is expected

Acute infection

This usually comes on very suddenly and is typified by some pain, swelling and redness of the affected limb. You will feel unwell and it will be quite apparent that there is an infection somewhere in the body. Although serious, this infection can usually be treated and it is essential that you should contact the ward immediately if you think your prosthesis is acutely infected. If the prosthesis is washed out and high doses of antibiotics are given, the infection can be stopped and the problem resolved in up to half the cases. The great necessity, however, is for prompt and immediate action.

Chronic infection

Unfortunately this is the more common kind of infection and is usually due to bacteria of a fairly low virulence. It presents in the same way as loosening with aching pain and discomfort but is also often associated with increasing stiffness of the limb. Chronic infection can develop at any time and is not necessarily associated with infection elsewhere in the body. Whenever a prosthesis is loose we have to check that there is no chronic infection present and we do this by taking some fluid out of the prosthesis cavity under a local anaesthetic. This is called an aspiration. Chronic infections do not respond to antibiotics. Whilst it may stop the situation getting worse, it will never cure the infection. The only way we have of controlling this infection is by doing what we call a two-stage revision. This means taking out the prosthesis and the cement and inserting a temporary spacer in the gap that is left full of antibiotic. Six weeks later a new prosthesis is inserted. Using this technique 85% of infections can be controlled but some continue to be a problem. A further revision can be attempted but is not always successful. Persisting infection is unfortunately the most common reason why amputations have to be carried out following EPRs.

Local Recurrence

One of the problems of limb sparing surgery is a slightly increased risk of tumour cells being left behind. If these continue to grow they may present as another small localised tumour, which is known as a local recurrence. Part of the reason for follow up is so that we can detect this early by examining the limb and also by taking X-rays. If local recurrence is detected early it can usually be removed surgically but we would then almost always want to give radiotherapy as an insurance policy to try and stop any

further problems returning. If a local recurrence is large by the time it is diagnosed the only option may be an amputation.

If you have any problems with your wound contact your keyworker or Ward 11/Ward 3

The Bone Tumour Team

The Bone Tumour Team at The Royal Orthopaedic Hospital consists of a multi-disciplinary team of professionals.

Contacting the Bone Tumour Team

Department	Direct Line
Royal Orthopaedic Hospital	0121 685 4000
Ward 11(children)	0121 685 4011
Ward 3 (adults)	0121 685 4012
Physiotherapy	0121 685 4120
Specialist Nursing Team	0121 685 4031

Consultant Surgeons

We have a team of Consultant Surgeons here at the Royal Orthopaedic Hospital. They are all specialists in the surgical management of bone and soft tissue tumours.

Nurse Consultant

The Nurse Consultant is a highly specialised nurse with vast experience in nursing patients who have bone and soft tissue tumours.

Nursing Staff

A team of qualified nurses, some of which are specialised in orthopaedics and oncology, are there to help with any of your nursing needs. They will also help to maintain your mobility in between physiotherapy sessions. On the children's ward the qualified nurses are all R.S.C.N (children's nurses).

Physiotherapists

The Physiotherapists are responsible for your rehabilitation after surgery. This may include teaching exercises and showing you how to walk after surgery. They will also make sure that you are safe to be discharged from hospital.

Macmillan Keyworker

The Macmillan Nurse is a specialist nurse who is experienced in caring for patients with cancer, particularly bone and soft tissue tumours. They are able to provide information and advice and the opportunity to talk about diagnosis and treatment. Their role as a key worker helps to co-ordinate the journey throughout treatment and provides contacts for continuing support at home. The nurse is also able to provide more specialised support for individual patients who may have developed further problems or challenges related to their disease or treatment.



Occupational Therapists (OT's)

The OT's are concerned with your independence after surgery and before you are discharged home. You will be able to try out everyday tasks on the ward and if you need basic equipment to assist you using the toilet or bath, getting from bed to chair, dressing independently or performing tasks in the kitchen. They will organise for the provision of this equipment. If home adaptations (e.g. stair rails are needed), a referral will be made to your local area for measuring and fitting of these.

Dental Surgeon

Our Dentist will see you on the ward for a dental check-up before you have your surgery. If you need any treatment this will be arranged locally. The recommended antibiotic regime for dental procedures is: Cephalexin, Cephadrine or Amoxicillin-3G orally / IM one hour prior to procedure. If allergic to penicillin then use Clindamycin 600mg orally / IM one hour prior to procedure.

School Teachers (Ward 11)

There are qualified Teachers on ward 11 who will talk to you about school and when you feel well enough will help you to continue your studies.

Social Worker (for patients under 21yrs)

The Social Workers provide advice or support during and after your treatment. They provide an opportunity to talk through the diagnosis and treatment and its impact upon your lifestyle and family.

The services offered are as follows:-

- **Counselling Service**
- **Practical advice and support**
- **Discharge arrangements**
- **Support after discharge**

Frequently Asked Questions

How much will my prosthesis weigh?

Approximately 1½ times the weight of the bone that has been replaced. You will notice this when you move.

How will my leg look and feel following my operation?

Your leg will have quite a long scar and may be swollen. For the first 2–3 days you may feel that your leg is heavy and numb. This is due to swelling. This will soon improve as you begin to exercise and start to walk.

Will I experience any problems with my prosthesis when flying?

You will need to discuss with your doctor if you are planning a long haul flight. The doctor can then advise you of any up to date precautions. You should not fly for the first 3 months after having a joint replacement. If you are going on a long haul flight you need to be aware of the risks of DVT and take precautions for this, as advised by your GP. Each airline has its own regulations about flying after surgery. Check with your airline before you fly.

Will my prosthesis activate the airport security?

Sometimes this does happen, so you will be given a card to carry with you just in case!

When can I resume sporting activities?

For the first six weeks there are likely to be certain exercises/ activities that you are restricted from doing. We normally suggest that you complete your week of physiotherapy first and then we can advise you when and what to start. High impact exercise and contact sports are best to be avoided.

When can I resume normal sexual relations?

As comfort allows, although you may, need to be careful with your choice of position in the first 3 months.

When can I start driving again?

At the earliest following your week of intensive physiotherapy or take advice at your first follow up appointment.

How long will the scar be on my limb?

This depends on the type and size of your prosthesis. You can ask to see your prosthesis before surgery if you would like.

What happens if I have a problem out of hours?

In the first instance contact the ward if they can't resolve the problem they will put you in touch with the "on-call" doctor.

Is the risk of recurrence higher with limb sparing than amputation?

Yes. Because we have to try and preserve the muscles around the tumour there is always a small risk of some tumour cells being left behind? We know that the risk of local recurrence is increased by a poor response to chemo and by a large tumour. If this is the case, then in some cases amputation may be advised. There is no evidence that amputation improves survival over limb salvage surgery.

Information for patients and carers

What is available?

Macmillan BACUP information booklets on the different tumours that we treat

- Information on support groups for patients / carers
- Macmillan Cancer Support Information booklets
- Information on benefits

Where?

Day Room Ward 3 Information booklets
Information Booklets Hub in Outpatient Clinic

Who can help?

- Any of the doctors, nurses, physiotherapists or occupational therapists based on Ward 3.
- The Nurse Specialists in Orthopaedic Oncology: 0121 685 4031

Websites

Macmillan Cancer Support	www.macmillan.org.uk
CarersUK	www.carersuk.org
Cancer Research UK	www.cancerresearchuk.org
NHS Choices	www.nhs.uk
Teenage Cancer Trust	www.teenagecancertrust.org
Sarcoma UK	www.sarcoma.org.uk
Bone Cancer Research Trust	www.brct.org.uk

Confidentiality

The Trust is committed to keeping your information safe and secure, and to protecting your confidentiality. For more information about how we do this please read the Trust's leaflet: "**Ensuring information confidentiality**" this is available in waiting areas, on the Trust website or can be requested through the Communications team on 0121 685 4379

Patient Support

Our Patient Advice and Liaison Service (PALS) offers help, support and advice to patients, their relative, friends and carers. PALS can help answer questions you have about hospital services; respond to problems or concerns; and welcome suggestions or comments, both positive and negative. PALS can be contacted Monday to Friday- 8.30am and 4.30pm on 0121 685 4218.