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The Royal Orthopaedic Hospital
NHS Foundation Trust

Royal Orthopaedic Hospital NHS Foundation Trust Patient Information

Proximal Humeral Endoprosthetic Replacement

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

Information and Advice

Contents

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 area at the back of the booklet.

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Before your operation

You will be admitted to one of the wards a day before or on the day of 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 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. They will discuss with you any worries or concerns about pain management following your surgery. You will be seen on one of the main 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

You will be fasted for theatre. You can have food until midnight the day before and allowed water until 6am on the day of 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 you will be transferred to the operating theatre for the surgeons to 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 and an opsite dressing (a clear plastic film) which will cover the wound for 2 weeks, or skin clips.
- A pressure bandage (a soft bulky dressing) will be wrapped around your arm.
- 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.
- You will then be transferred back to your original ward.

Pain control

There area a number of methods of pain relief. You will be connected to a machine that contains a supply of pain relieving medicine. There will be a tube leading from the pump into a vein in your arm (IV). 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 painkiller 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. To make sure that you do have good pain relief the nurse will ask you to describe your pain on a scale of 1 -3:

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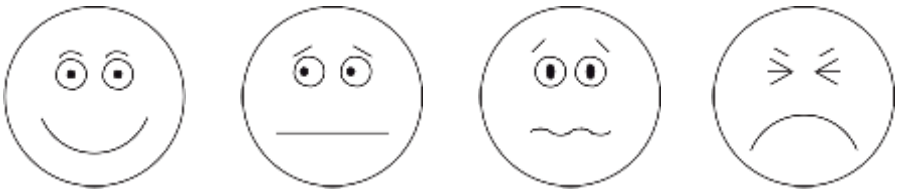
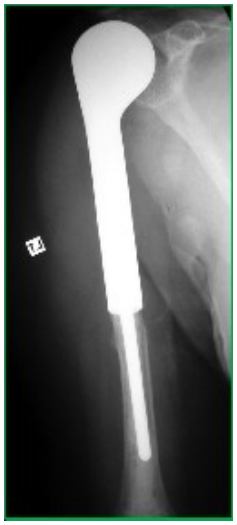
1	2	3	4



NO PAIN	SOME PAIN	BAD PAIN	SEVERE PAIN

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 Physiotherapists 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.

Proximal humeral endoprosthetic replacement (PF EPR)



This EPR replaces the upper part of your humerus (upper arm bone). The majority of the muscles that control your shoulder movement attach to the top end of your humerus. During the operation, these muscles will be re-attached to each other in a mesh over the top of the prosthesis.

After your surgery

You will return to the ward with your arm in a sling and you will be able to walk around as soon as you feel able. On the first 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. Instructions will be given by the nursing staff about caring for your wound and after care following discharge. You will be given anti-embolic stockings to reduce the risk of a blood clot, to wear for up to 6 weeks post surgery.

Physiotherapy

Physiotherapy normally starts on the first day after your operation. The Physiotherapist will concentrate on gaining and maintaining movement at the wrist, elbow and shoulder girdle (shoulder blade). These joints will be vital in allowing useful function in your arm in the future. You should only remove the sling to do your exercise or when dressing. An exercise sheet will be provided to remind you of your exercises. You will be guided by the physiotherapist as to how much exercise to do and when. The movement at your shoulder will be restricted for 6 weeks by using a sling. This is to allow the muscles to heal. During this time you will be allowed to wash and dress with care.

The Occupational Therapist will teach you how to do this safely and advise you of any aids or adaptations that you may need to help you to dress and function independently. You should expect to stay in hospital for between 4-7 days, depending on your progress. The physiotherapist and nurses will tell you how you are getting on so you can

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make plans for going home. The physiotherapists will give you a date for your week of intensive rehabilitations, and a home exercise programme. This is usually around six weeks after your operation. You will be advised to continue your and progress your independence as you feel able until you come back for physiotherapy. If your physiotherapist thinks that it is appropriate, they may refer you for further in or outpatients treatment nearer home. We will contact your local physiotherapy 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?

- Wash and dress independently
- Take your sling off and put it back on correctly
- Perform a home exercise programme independently

You must not let your arm hang unsupported at any time in the first month. You can gradually wean yourself out of the sling, but continue to wear your sling if you go out or if your arm becomes tired.

Things to avoid with an EPR

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

If you have non-invasive growing EPR you must not have an MRI

If you have any other questions about sport activity please ask any member of the Bone Tumour Team.

Your intensive physio 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 are loose tracksuit bottoms
- Your will also need to bring your swimming costume

What happens during the physio week?

- Most people really enjoy their week of physio. It is tiring but very worthwhile!

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- The physio will assess you and plan a treatment program with you
- You will spend most of your day either in the hydrotherapy pool or in the gym
- You will also have the opportunity to speak to the doctors if you have any questions

Don't worry if you have a Hickman Line or a PICC (peripheral inserted central catheter) Line as these can be covered up for hydrotherapy.

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

What can I expect after 3 months?

- You should have almost full movement at your elbow
- You should have full movement at your wrist and hand
- You will be able to use your arm functionally for washing/dressing, but your shoulder movement will be very limited
- You are unlikely to be able to lift your arm above your head
- Some activities of daily living will be awkward, such as pegging out washing, or reaching to a high shelf
- You will need to rely on 'trick' movements to move your shoulder
- You will be able to drive a car (if you have a licence!) but you must let your insurance company know about your EPR
- You will be able to swim and cycle but high impact activities and contact sports should be avoided

In general the maximum function will be achieved by about six 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.

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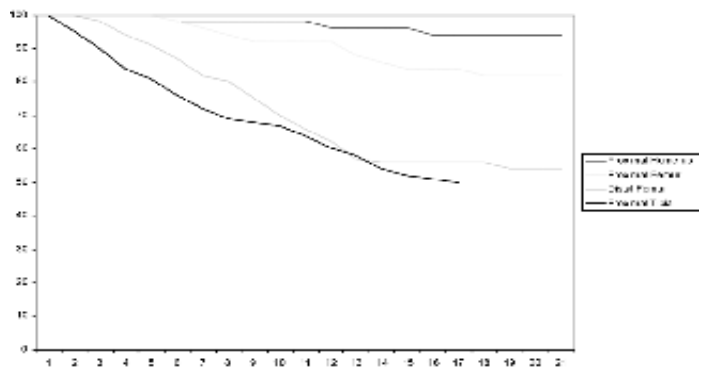
What can go wrong?

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 arm fairly frequently over the years simply to make sure that the prosthesis is not working loose. If it does work loose it needs to be re-fixed into 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. The graph below shows the chances of a prosthesis failing for whatever reason.



It shows the survival curve for the 4 main types of EPR showing that time 0 (the day of the operation) 100% are normal and that by 10 years, approximately 90% are still working fine.

Infection

Infection is the most significant complication that can develop. Because the EPR is made of foreign material, the body has difficulty combatting 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 any of the following dental procedures you should have antibiotics prescribed for you: (see information further on).

Root canal surgery / Dental extractions

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

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

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Acute infection

This usually comes on very suddenly and sis 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 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 a high dose of antibiotic 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 antibiotics. 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 slight 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. Prat of the reason for follow up is 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(children)or Ward 3(adults).

The Bone Tumour Team

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

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

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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).

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**

Macmillan Keyworker

The Macmillan Keyworker is a specialist nurse who is experienced with 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.

Physiotherapists

The physios are responsible for your rehabilitation after surger6. this may include teaching exercises and showing you how to walk after surgery. They will make sure that you are safe to be discharged from hospital.

Occupational Therapists (OT)

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, Cephradine or Amoxicillin-3G orally/IM one hour prior to the procedure. If allergic to penicillin the use Clindamycin 600mg orally/IM one hour prior to procedure.

School Teachers (Ward11)

There are qualified teachers on Ward 11 who will talk to you about school and when you feel well enough will help you continue your studies. They will contact your school for information so you are working at the correct level and will liaise regarding support following your operation. Pupils in years ten and eleven area able to do their G.C.S.E.

course work and can even take exams in hospital if necessary.

Social Worker (patients under 21)

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

How will my arm look and feel following my operation?

Your arm will have quite a long scar and may be swollen. For the first 203 days you may feel that your arm is heavy and numb. This is due to swelling. This will soon improve as you begin to exercise.

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 relation?

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 physio or take advice at your first follow up appointment.

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Is the risk of recurrence higher with limb salvage 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.

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.

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 benefit

Where?

- Day Room Ward 3
- Information Booklets
- Computers
- 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
Carers UK	www.carersuk.org
Cancer Research UK	www.cancerresearchuk.org
Cancer Black Care	www.cancerblackcare.org.uk
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

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