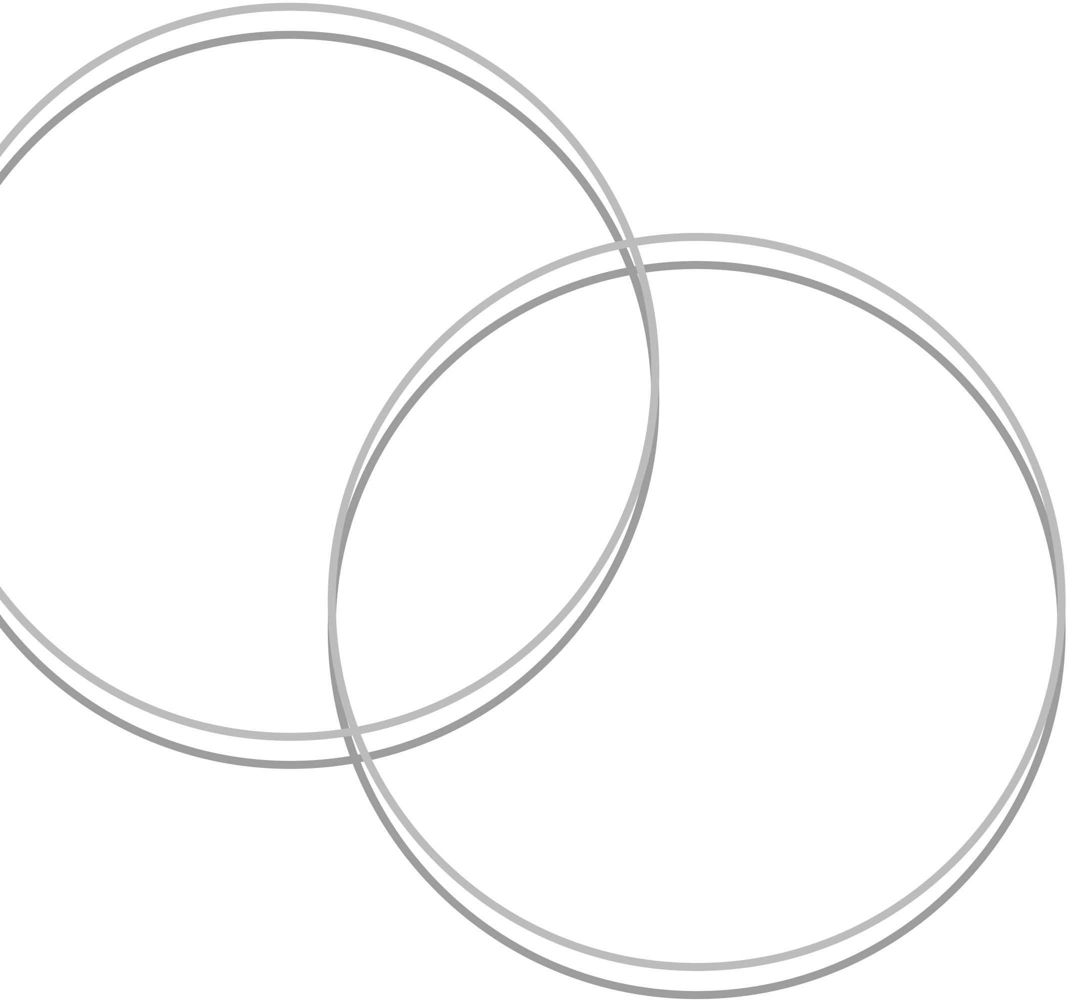
Oxford University Hospitals
NHS Foundation Trust

Surgery for Pelvic Sarcoma

Information for patients



Introduction

You have been offered a surgical procedure by your Oxford Sarcoma Service surgeons to remove a pelvic sarcoma (a tumour in your pelvis).

We have produced this leaflet to give you general information about the procedure. It is not intended to replace the discussion between you and the healthcare team, but may act as a starting point for your discussion. If you have any concerns or need anything explaining after reading the leaflet, please discuss this with a member of the healthcare team.

What is surgery for a pelvic sarcoma and what does it involve?

Surgery for a pelvic sarcoma is called a pelvectomy or a hemipelvectomy. It is performed following the results of investigations (such as scans), a discussion at a multidisciplinary team meeting involving experts in this field and detailed consideration by your consultant. The surgery can be carried out in various ways.

The surgery usually involves making a large cut on your side, between your ribs and your hip (your flank) or at the front or back of your hip. Often, your surgeon will make cuts in a combination of these places, which they have carefully chosen to allow them to access the tumour. The surgeon will then remove the tumour and part or all of the pelvic bone, depending on your particular case. They may then carry out a reconstructive procedure. This could include reconstructing the bone, the hip joint or the soft tissue, and might involve plastic surgery to close your wound safely.

The other option that you might be offered is called an external hemipelvectomy. With this type of surgery, because of the extent of your disease, it is not possible to save your leg and the operation involves amputating it higher than the pelvis.

With an external hemipelvectomy, you may sometimes need further surgery to the blood vessels and nerves, bowel, bladder and ureters (the urine tubes which connect your kidneys to your bladder). A plastic surgeon may be involved to close your wound safely using a flap of skin or a skin graft (where a section of skin is taken from another part of your body to close the wound). If this is necessary, you will meet the plastic surgeon before your operation.

If there is a significant risk of injury to your bowel or a planned bowel resection is needed to remove a damaged or diseased section of the bowel, the bowel surgeon may have to form a stoma by bringing part of your intestine out onto the surface of your abdomen (tummy) so that your bowels empty into a bag. Your surgeon will explain why this needs to be done in your case. Similarly, if the urinary bladder is at risk, your ureters could be brought out to the surface of your abdomen so that your urine can be collected in a bag, which is usually connected to the bladder by a tube. Although most patients do not need this extra surgery, your consultant will discuss your individual risk with you.

Why do I need surgery for pelvic sarcoma?

This operation is needed to remove a tumour from your body because it could be life-threatening or could lead to you needing to have your leg amputated. The decision to perform the surgery is usually made in a large multidisciplinary team meeting (one involving healthcare professionals with different medical expertise). The meeting will take place in a specialised centre and Oxford University Hospitals is one of the few hospitals to carry out these operations.

After the operation your tumour will be sent for final testing to assess whether you need further treatment.

The extent of the surgery depends on the size of the tumour and how aggressive it is.

Are there any complications or risks?

There are risks associated with all operations carried out under general anaesthetic. We will take every care to keep the risks of your surgery as low as possible.

The possible complications include the following.

Infection and wound breakdown – The risk of an infection after surgery is reduced by giving antibiotics around the time of surgery. These aim to prevent infections, but infections can still develop in the pelvis, bladder, chest or wound.

Superficial infections, involving the skin only, are usually easy to treat with antibiotics. Occasionally a deep abscess may form. This is a collection of pus, and you may need more surgery to drain it under anaesthetic. The overall risk of infection and wound problems is about 30% here in Oxford, which is the same as or lower than other major surgical centres.

If you have had reconstruction surgery involving metal implants, any infection involving these could mean that they have to be removed, although this is rare.

Sometimes you may need further plastic surgery to close the wound if a large area of skin does not heal.

Bleeding – This may happen during the operation or, rarely, afterwards and you may need a blood transfusion during or after your operation. This is necessary in most cases of pelvic sarcoma surgery even though we take care to reduce blood loss as far as possible, including using advanced measures such as cell-salvage equipment. This is a device that recycles and gives you back some of the blood lost during the operation.

Major haemorrhage can be life-threatening and can mean you need massive blood transfusions or further procedures to save your life. This is very rare, and there is a very small risk of it happening in pelvic surgery (in about 1% to 2% of cases). This happens if one of the many large blood vessels that run through the pelvis is damaged, causing rapid loss of blood.

Occasionally, blood collects in the surgical site (the part of the body where you had the surgery). This is called a haematoma and it may need to be drained under general anaesthetic.

If you have special circumstances, for example if you are a Jehovah's Witness, we will discuss all options with you.

Injury to the bowel or bladder – Your bowel and bladder are close to where the surgery will be performed and they can sometimes be accidentally damaged during the operation. This can be challenging because you will need surgery to repair the damage and form a temporary or permanent way for urine and faeces (poo) to leave your body. This will normally be in the form of a stoma on the surface of your abdomen, as already explained.

You are likely to have some difficulty passing urine after surgery due to pain, lack of mobility or other restrictions depending on the type of operation you are having. To ease this, your medical team may decide it is necessary for you to have a catheter in your bladder to take away urine and collect it in a bag outside the body. This may only be for a few days but sometimes it may be necessary to leave the catheter in for longer.

In very rare cases, your surgeon will decide beforehand that you need to have your bladder or bowel removed during your surgery and, if so, a stoma will be formed as a part of the operation.

Deep vein thrombosis and pulmonary embolism – It is possible for blood clots to form in the deep veins of the legs and pelvis. This is called a deep vein thrombosis (DVT). It will normally cause pain and swelling in the legs and can be treated relatively simply with drugs. However, in rare cases, a clot breaks away and travels to the lungs or heart (pulmonary embolism). This is a serious condition and could be life-threatening.

The risk of developing a DVT is low (2%), as many precautions are taken to help reduce the risks. Moving around as soon as possible after your operation can help to prevent this. We will give you surgical compression stockings to wear while you are in hospital, and injections to thin the blood. See the separate patient information sheet, 'Venous Thromboembolism (VTE) – Reducing the Risk', which you will be given during your pre-operative assessment visit.

Injury to your ureters – This complication is very rare. The ureters are the tubes that connect your kidneys to your bladder. It is possible for them to be injured during surgery and you may need further surgery if this happens.

Tumour growing back – There is a higher chance of a tumour growing back if the original tumour has not been completely removed or the distance between the tumour surface and the cut the surgeon has made is very small (known as a very close margin).

If the surgeon has not been able to remove all of the tumour and there is a possibility that some of it has been left in your body (there are incomplete margins), soon after the surgery you may need to have another operation to remove the remaining tumour from your body. Whether this is necessary will depend on the exact nature of the tumour and whether there are any other treatments to control it.

For a large tumour, the overall risk of it growing back can be as high as 8% to 12% in the first 12 to 18 months but this reduces over time.

Implant failure and dislocations – Your surgeon might discuss with you a plan to reconstruct your pelvis or hip joint. This would normally mean using metal implants but can also involve using bone taken from other parts of your body or from a donor who has died.

If your surgeon has planned to reconstruct your pelvis or hip joint with a metal implant, the overall risk of problems arising from this additional procedure is 10% in Oxford, with the risk of dislocation of the hip joint accounting for 6% of these. Again, these risks are similar to international figures. You may need further surgery to fix any problems with the implant.

Other complications could mean that the implant may stop bonding with your bone and become loose. Also, as is the case with most metal implants, routine wear and tear may arise over time and you might need another operation to replace the implant in the future.

Risk of bone injury or fracture – There is a small chance (usually less than 1%) of an accidental fracture during the operation. This can happen either when your surgeon is removing the tumour from the bone or when metal implants are being fixed to your pelvis as part of the reconstruction.

Usually, these fractures are seen during the operation and your surgeon will fix them. This could mean that your mobility is restricted after the operation to allow the fracture to heal. Occasionally these fractures are picked up in X-rays after the operation. This is rare, but could mean you need another operation to fix the fracture.

Risk of serious medical complications and death – Your surgeon will discuss your individual risk with you.

Major pelvic surgeries carry a risk of significant medical complications, including the risk of having a stroke or a heart attack. The risk of having a major medical complication is about 1% to 2%. Unfortunately, although rare, this can result in death. Before your operation you will have a thorough assessment by our anaesthesia team, who are very experienced in carrying out these operations, to make sure you have had the correct risk assessment and are in your best shape to have the operation.

Other complications – The skin around the wound will usually be numb for several months after the operation. This usually improves within six to 12 months. This is due to the nerves healing and reconnecting after surgery. There can be other risks and it is not possible to include them all in this document.

We would encourage you to discuss your individual risks with your consultant when giving your consent for the operation.

How do I prepare for my operation?

Share this information with your family (if you want to) so they can help and support you. There may be information they need to know, especially if they will be taking care of you after your operation.

Our team of specialist physiotherapists and occupational therapists will assess what mobility aids and arrangements you will need when you leave hospital, and will help your family and friends make sure you recover quickly and safely.

Feel free to ask as many questions as you want. Most patients find it quick and easy to contact our specialist nurse team.

What will happen after my surgery?

It is important to keep your wound clean. To avoid the risk of contamination and moisture affecting your wound, we generally recommend sponge baths instead of showering or bathing until the wound has healed and the skin has sealed.

To further reduce the risk of infection, a member of your healthcare team will inspect your wound dressing every day while you are in hospital. You will have stitches or staples in your wound. These will be removed no earlier than 14 days after your operation. Sometimes the stitches are dissolvable and do not need to be removed.

Most patients stay in hospital for five to seven days after the operation, but this will depend on the extent of your surgery.

When will I get my results?

After your operation the tumour will be sent for testing. The test results will not usually be available before you leave hospital. About two to three weeks after your operation you will have an appointment at an outpatient clinic to discuss the results and, if necessary, any further treatment. Plans for any further treatment are usually made beforehand in the same multidisciplinary team meeting that decided your operation in the first place. If you need further treatment, this may be at your local hospital or back in Oxford, depending on the treatment.

You will probably need to have regular follow-up appointments once your treatment is finished. This will normally be for 10 years after the surgery – every three months at first, then every six months if you are cancer-free after two years. For the last five years you will normally have a follow-up appointment once a year. Some patients prefer to remain under our care for the rest of their lives, and you are perfectly welcome to do this.

Useful contacts

If you need more advice, please contact the sarcoma clinical nurse specialists, who will be happy to speak to you. You may find it helpful to write down any questions you have so that you don’t forget to ask them when you speak to a nurse specialist or go to your appointment at the hospital.

You can email the sarcoma clinical nurse specialists at: **sarcoma.referrals@nhs.net** or call them on: **01865 738061**.

You can also visit our website at: **www.ouh.nhs.uk/oxfordsarcomaservice/**

Consent to treatment

Before any doctor, nurse or therapist examines or treats you, they must ask for your consent (permission). In order to make an informed decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. You should always ask them more questions if you do not understand anything or if you want more information.

The information you receive should be about your condition, the alternatives available to you, and details of the risks as well as the benefits. It is important that your consent is genuine and valid. That means you must:

- be able to give your consent
- be given enough information to be able to decide whether to give your consent, and
- be acting under your own free will and not under the strong influence of another person.

Information about you

We collect and use your information to provide you with care and treatment. As part of your care, we will share information about you between members of the healthcare team. This may include some people you will not meet. Your information may also be used to help train staff, to check the quality of our care, to manage and plan the health service, and to help with research. Wherever possible we use anonymous data (information which has personal details, such as your name, removed).

We may pass relevant information to other health organisations that provide you with care. All information is treated as strictly confidential and is not given to anyone who does not need it. If you have any concerns about this, please talk to your doctor or the person caring for you.

Under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, we are responsible for keeping any information we hold about you confidential. For further information visit the following website: **www.ouh.nhs.uk/privacy/**

If you (or your carer) need information about your health, wellbeing, care and treatment in a different format, such as large print, Braille or audio, please tell a member of staff and they will arrange this for you.

Notes

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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