

Pelvic exenteration

Information for patients
and their families/carers



Your doctor has recommended that you have an operation to remove your rectum, bladder and (if you are male) possibly your prostate. This operation is known as pelvic exenteration.

To allow you to still pass faeces and urine, we may also recommend that you have a special combined stoma constructed. This is explained later in the leaflet.

We hope this leaflet will help you to understand what this operation involves and how it will affect you.

It is natural to be anxious and nervous about the operation. It is important that you and your family talk to the Advanced Nurse Practitioner or surgeon about your concerns or any questions that you have. They will be able to explain all the information in this leaflet in more detail.

You can contact the Colorectal Advanced Nurse Practitioner and Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner at the following hospitals:

John Radcliffe Hospital

Tel: **01865 221 839** or **01865 221 454**

(9.00am to 5.00pm, Monday to Friday, excluding bank holidays)

Churchill Hospital

Tel: **01865 235 367**

(9.00am to 5.00pm, Monday to Friday, excluding bank holidays)

It is often helpful to have a partner, family member or friend with you when you have your appointments at the hospital. They can make notes and help with remembering what was discussed.

Why do I need this operation?

This operation is usually carried out for people who have cancer affecting their rectum, bladder and/or prostate (in men) or urethra (in women).

If you are having this treatment for cancer, the surgeon will also remove some of the healthy tissue around the tumour, to make sure all the cancer is removed.

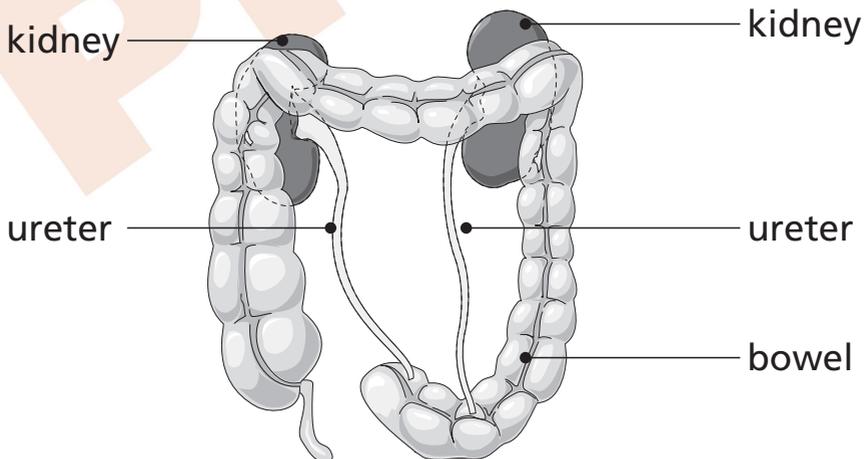
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What does the operation involve?

The operation will involve open surgery, not keyhole surgery. This involves making a cut down the centre of your abdomen (tummy). When your rectum is removed, you will no longer have an anus through which to pass a bowel motion (stool/poo/faeces). The removal of your bladder and prostate (if you are male) means you will also no longer be able to pass urine in the usual way. Your ureters (tubes from your kidneys to your bladder) will be attached to your bowel (sigmoid colon).

The surgeon will then use some of the lower part of your large bowel to create a tube (colostomy or 'stoma') to the outside of your abdomen. The stoma will be used to divert your urine and faeces, so it all flows out through this opening and into a secure bag. This is a type of combined stoma known as a 'wet colostomy'.

The operation will involve using a part of your abdominal muscles to cover the operated area and close the anus.



We will encourage you to get up and move around with help, within 24-48 hours of your operation. However, you will also need to make sure you regularly rest in bed, to help you recover. You will have drips and drains attached to you, but the nurses will help you with these when you need to move.

It is important that you start to walk around as soon as you can, as this will help increase your breathing and circulation. It will also help you to regain your strength, as well as reducing some of the risks associated with surgery, such as blood clots, chest infections and pneumonia.

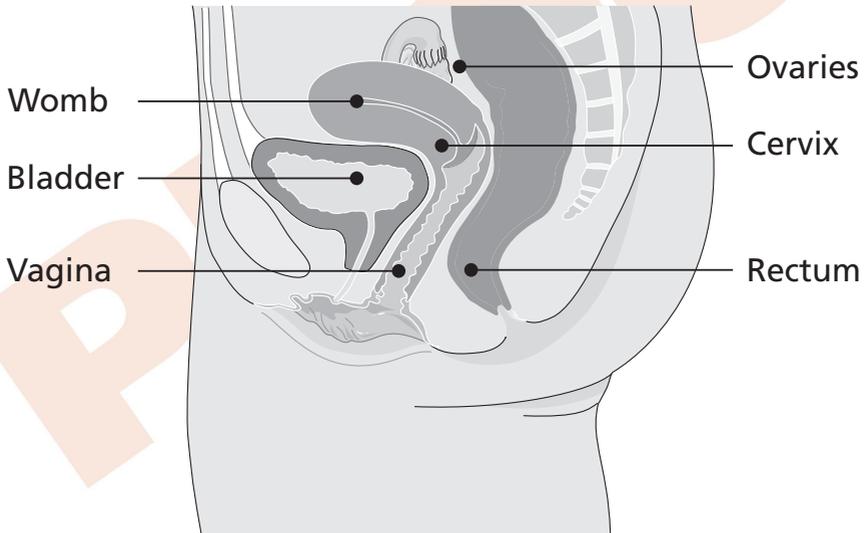


Illustration showing the female pelvic organs. We will show you the areas that will be removed during your operation.

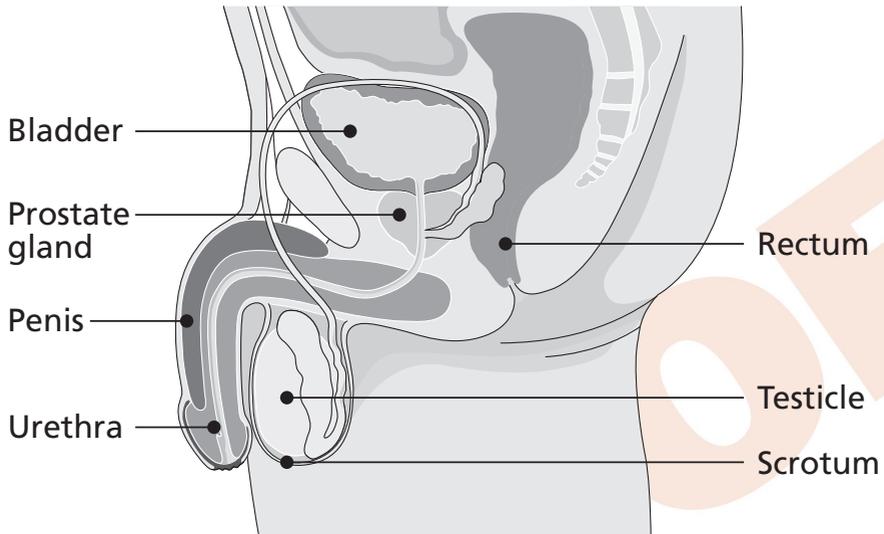


Illustration showing the male pelvic organs. We will show you the areas that will be removed during your operation.

Creating a stoma

Your surgeon will have told you that this operation will result in you needing a permanent colostomy or 'stoma'. A stoma is a surgically created opening on the abdomen, which allows faeces or urine to exit the body and pass into a secure, disposable bag. The type of stoma you will have will collect both faeces and urine into one bag.

The Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner will talk to you in more detail about this part of the operation, and will explain all you need to know about caring for your stoma once you leave hospital.

The Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner will also be able to give you a lot of information about recovery from the operation and life with a stoma. This will include advice about things such as work, travel and diet, which will help you to return to your normal everyday activities.

How long does the operation take?

This operation itself usually takes between 8 to 10 hours, but you will be away from the ward for longer than this, as you will be taken to the recovery area after your operation. Due to the length of time in theatre and the complexity of your surgery, you will then go to the Intensive Care Unit for added support after the surgery.

There will be three types of surgeon involved in your surgery:

- A colorectal surgeon, to remove your rectum and create the stoma.
- A urologist, to remove your bladder and/or prostate and attach your ureters (kidney tubes) to your large bowel.
- A plastic surgeon, to assist with the muscle flap to cover over your bottom area (by using a piece of your abdominal muscle to cover the area between your genitals and anus).

How long will I be in hospital?

The average length of stay in hospital is about 10-14 days; however, this can vary considerably from person to person, depending on how well you recover and whether you have any other medical requirements.

What are the risks?

This is a major operation and, as with any operation, it will carry risks. The chance of any of these risks happening varies from person to person, depending on lots of factors, such as age, weight and general health. Your surgeon and Advanced Nurse Practitioner will explain what the chance is of these risks affecting you, as well as any specific risks which might also apply to you.

General risks of surgery include:

- risks related to general anaesthetic (these will be discussed with you in more detail by the anaesthetist before your surgery)
- blood clots in the leg or lung (thrombosis)
- chest infection
- urinary infection
- myocardial infarction (heart attack)
- stroke
- death.

Specific risks of this operation include:

- bleeding
- wound infection
- deterioration of the muscle flap
- formation of internal scar tissue (adhesions)
- leakage from the point where the ureters join the large bowel
- damage to the nerves supplying the sexual organs (this could affect your sexual function). This can vary if your prostate is removed and may even be permanent.
- a very small risk of injury to the spleen (a small organ in the abdomen that plays a part in the body's immune system) and ureter (tube that drains the kidney) during surgery.

If there is anything you are unsure about, or if you have any questions, please speak to your surgeon or Colorectal Advanced

Nurse Practitioner before signing the consent form for the operation to go ahead (either at your pre-operative assessment or on the day of your admission).

What pain relief will I be given?

This is a major operation, so you will feel sore and uncomfortable afterwards; most people describe feeling very bruised. As the swelling from the operation goes down, this discomfort will also lessen. We will do our best to make sure that you have all the pain relief that you need.

Before your operation the anaesthetist will talk to you about the options for pain relief after the operation. You may have an epidural (spinal pain relief), or possibly a self controlled pain relief pump (PCA) for the first few days after your operation. You will receive a leaflet explaining this in more detail, during your pre-operative assessment appointment.

The nurses on the ward will regularly ask you about your pain to make sure that it is under control and will give you further pain relief if you need it.

After the operation

You will have a bag over your stoma that will be emptied regularly by the nurse, until you are able to do this yourself. Urine will pass into the bag immediately after the operation and faeces will usually start to pass after 24-48 hours. At first, your faeces will be liquid; this is normal and as your appetite increases they will become firmer and well-formed.

The exit site where your stoma opens from your abdomen will be swollen to begin with. There will be a plastic rod (7.5cms in length) supporting your stoma for the first 5-7 days and you will also have dissolvable stitches surrounding the edge of the stoma. The removal of this rod is straightforward and your Advanced Nurse Practitioner or ward nurse will be able to carry this out. This should not be painful.

You will also have two stents (thin, long plastic tubes) which go through your stoma and into your bowel, to support the join between the ureter (kidney tubes) and the bowel. These will stay in place for approximately 10-14 days. As they are held in place with dissolvable stitches, they will either fall out when they are ready or can be removed by your Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner.

What is enhanced recovery?

Enhanced recovery is a new way of improving the experience and wellbeing of people who have had surgery. It can help you to recover sooner, so that life can return to normal as quickly as possible. The programme focuses on making sure that you are actively involved in your recovery. This will be discussed with you at your pre-operative assessment appointment.

Sitting after surgery

After surgery on your bottom, you will be advised by your surgeon not to sit on this area for long periods of time. You may need to lie down regularly to avoid pressure on the wound while it is healing.

Immediately after the surgery, the nurses will help to keep you comfortable and will help you into positions to avoid putting pressure on your healing wound. Your surgeon will tell you how long you will need to avoid sitting on your wound after surgery, as this varies from person to person, depending on how quickly you heal and feel comfortable.

Getting back to normal

How soon can I drive after surgery?

Your nurse specialist will discuss this with you. Most insurance policies state that you are not covered until 6 weeks after abdominal surgery. This is because it is likely that your reaction time will be slower than normal if you have to complete an emergency stop. If you feel that you are safe and ready to return to driving before 6 weeks, please discuss this with your GP. They may be able to give you the 'go ahead' to drive and you can then check this with your insurance company.

When can I make love?

When you feel you want to!

The anxiety and stress of surgery can often reduce your sex drive. This is quite common and will return to normal in time. It is important that you and your partner take the time to talk about your feelings. This will help you both to relax more and enjoy your lovemaking when you feel ready to.

You may find that the surgery affects your sexual function. This affects men and women differently.

In men, after the operation the nerves controlling erection can sometimes be bruised, as they are located close to the rectum. If you are experiencing difficulties gaining or maintaining an erection, give yourself time to recover from the surgery. If this problem continues, please seek advice from your GP or Advanced Nurse Practitioner, as there may be some further treatment that can help.

If you are male and your prostate is removed during this surgery, there is a chance that problems with sexual function and/or impotence could be permanent.

If you are a woman, feeling nervous or anxious can make you tense. This can cause lovemaking to be uncomfortable and possibly

painful. The more relaxed you can be the better. Take your time and don't let yourself feel rushed if you are not ready. You may find that using lubricants or changing your position may help.

When can I return to work?

You can return to work when you feel ready to. Deciding when to return to work is an individual decision. If your job involves lifting, pulling, pushing or stretching, then it is better not to go back to work for 2-3 months. Returning to work with light duties to begin with may also help. If your job is very active, we recommend that you wear a hernia support garment, to reduce the chance of developing an abdominal hernia. Your Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner can give you advice on these, if you require it.

Developing a hernia is a common complication following the formation of a stoma. A hernia is described as a bulge or swelling, which forms as a result of a weakness in the abdominal wall. Not everyone with a stoma will develop a hernia, but if they do, how severe it is and how it impacts on stoma care will vary from person to person. We will give you further information on hernia prevention if we feel you will be at risk.

Tiredness

It is normal to feel tired when you go home from hospital. When you first get home from hospital after your operation, try to plan your time so that you have regular rests throughout the day.

It may take some time to return to your full strength. Please think about any support you might need during this initial recovery period at home, and talk to your Advanced Nurse Practitioner and the ward staff if you have any concerns. It may be a good idea to have a friend or family member stay with you when you return home, to help with shopping, cooking and cleaning. This will be a great help whilst you are feeling tired. If you have children or grandchildren you should also be cautious of picking them up, as this may cause an abdominal hernia.

Exercise

You should try to build up your strength slowly once you are home. Start by going for a short walk every day and increase this distance each time. The physiotherapist will show you some exercises while you are in hospital, which you can continue to do at home, to help to build up your muscle strength.

You will be able to return your normal activities when you feel well enough. If you normally take part in any regular sporting activities or exercise, these can be re-introduced into your routine slowly. Please speak with your surgeon or Advanced Nurse Practitioner before returning to contact sports, such as rugby.

Please take care when lifting, bending or stretching, particularly in the first few weeks after your surgery.

Pelvic floor exercises can be beneficial before your operation, to strengthen your muscle tone around your bladder and bowels. We can give you more information about these exercises before your surgery.

Wound care

It is likely that your tummy and bottom wounds will not be completely healed before you go home. They may need to be dressed by the practice nurse at your GP's surgery or, if you are unable to get there, your local district nurse will come out to you. This will be arranged by the ward nurse, before you are discharged from hospital.

Urinary infections

Due to the nature of this surgery (because your ureters are joined to your bowel) you will always be at potential risk of developing a urine infection. The symptoms of this are a fever (high temperature) and lower back pain, but the infection usually responds quickly to antibiotics.

Urinary infections can occasionally be caused by a narrowing or blockage in the ureters. This may need further investigation if it becomes a persistent problem.

Follow-up care

Your Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner will telephone you once you are home, to check everything is going well. They will arrange a home visit about 7-10 days after your discharge from hospital, to check the stoma and that you are coping well. Please contact your Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner if you have any concerns before this visit. It is sometimes good to write down your questions or worries, so you can ask them when they contact you.

If you live in a county outside of Oxfordshire we will refer you to your local team, to give you on-going support.

An outpatient appointment will be made for you approximately 2-4 weeks after your discharge from hospital. If you have any non-urgent questions, this is a good time to ask them.

At this stage we may discuss whether you need further oncological treatment, such as chemotherapy. As well as a routine follow-up with your colorectal surgeon (lead consultant), you will also have a follow-up appointment with the plastic surgeon, to make sure your wound is healing well, and the urologist, to check you do not have any urine infection symptoms.

Further information

Colostomy Association

Tel: **0800 328 4257**

Website: **www.colostomyassociation.org.uk**

Macmillan Cancer Support

Tel: **0800 808 00 00**

Website: **www.macmillan.org.uk**

Other patients or 'colostomates' are also available to be buddied up, for you to talk to before or after your operation. Please ask your Colorectal Advanced Nurse Practitioner, Stoma Specialist Nurse Practitioner or Advanced Nurse Practitioner for contact information.

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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