

Information for women having pelvic exenteration

Women's and Children's Division

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Information for Patients

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Introduction

This leaflet aims to answer your questions about having pelvic exenteration. It explains the benefits, risks and alternatives, as well as what you can expect when you come to hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

What is pelvic exenteration?

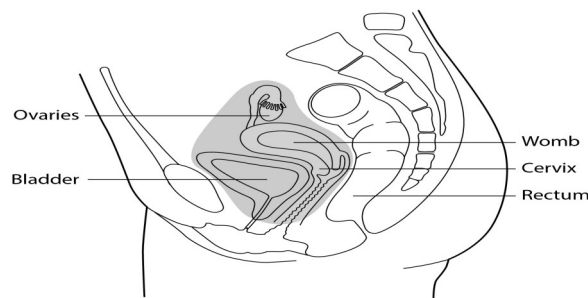
Pelvic exenteration is a major operation during which some of the organs of the pelvis are removed. This surgery is normally offered to women who has locally advanced cancer or who have already had treatments for their gynaecological cancer. The cancer has either returned or has not been cured by these treatments.

There are different types of pelvic exenteration and which type is needed depends on where your cancer is situated. Some women will already have had their womb or their ovaries, or both, removed in their initial treatment. Other women will not have had gynaecological surgery but received chemotherapy and radiotherapy. Some may have had both types of treatment.

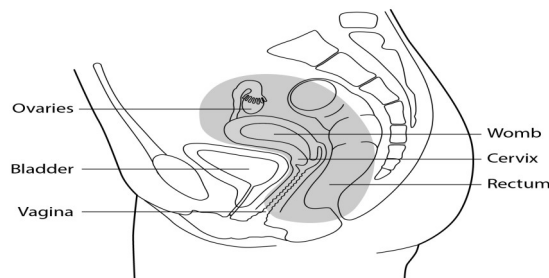
In the following diagrams on the next page the areas removed during the operation are shaded over.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

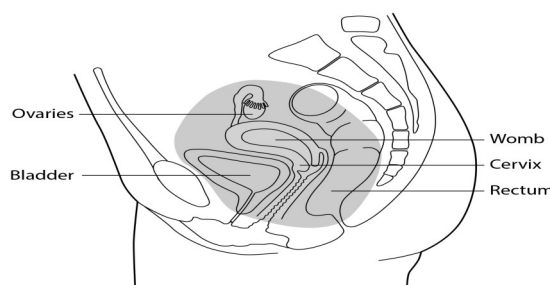
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Anterior pelvic exenteration (above) is used if the cancer is at the front of the pelvis. The internal reproductive organs and the bladder are removed. You will need a new place for urine to leave your body. The surgeon will make a new opening (a stoma) on your abdomen for this, called a urostomy.



Posterior pelvic exenteration (above) is used if the cancer is at the back of the pelvis. The internal reproductive organs and the lower part of the large bowel (rectum) are removed. The surgeon will make a new opening (stoma) on your abdomen for bowel motions to leave your body. This is called a colostomy.



Total pelvic exenteration (above) is used if the cancer is in the middle of the pelvis. The bladder, the internal reproduction organs and the rectum are removed. You will have a urostomy and a colostomy during the same procedure.

What is the aim of this operation?

Pelvic exenteration is carried out on ladies whose cancer has come back after initial treatment and this cancer is in the pelvis and has not spread elsewhere. The aim is to cure the patient of her disease. If you have symptoms in the area where the cancer has returned, the operation may relieve some of these symptoms.

What are the possible risks and complications?

As with any operation there are risks. Your doctor will explain these risks to you before you sign the consent form. This form confirms that you agree to have the operation and understand what it involves. Please ask questions if you are not sure.

Possible risks and complications from this surgery are:

- Bleeding during or after your operation: you may need a blood transfusion.
- Blood clots: you will be given a month's supply of anticoagulant injections to reduce your risk of getting a blood clot. You will be taught how to give these to yourself or a carer or district nurse can give them to you.
- Problems caused by having a general anaesthetic.
- Infections: you will be given antibiotics to help prevent this.
- Your wound could be slow to heal, or break down due to poor healing caused by previous treatments.
- The joins inside your body may come apart.
- A hole called a fistula can occur in the pelvis or abdomen due to having cancer treatments.
- Your bowel may become obstructed.
- Your kidneys may start to fail.
- Your ureters (the tubes that carry urine from the kidney to the bladder) may become blocked.

You will be watched closely in hospital and if any of the above happen, actions will be taken to prevent or deal with it.

This is a long list of risks and complications, but not all of these occur with every patient. If you develop any of these complications, you will be seen by your medical team and a course of action discussed with you. This may lead to you staying in hospital for longer.

These complications are rare, but you must be aware of them. As with any operation, there is a risk of death, although this is very rare. Please talk to your doctor about any concerns you have before your operation.

Are there any alternatives?

This operation is only performed if there is a good chance that it will cure your cancer. You will probably have had radiotherapy already. The highest doses of radiotherapy will have been used and radiotherapy cannot usually be used again in the same place, as it will cause too much damage to your bowel and bladder.

Chemotherapy and hormone treatment might keep your cancer under control, but neither will cure it completely.

What happens before my operation?

We will ask you to come to the hospital for a pre-admission appointment, so that we can do some tests and talk to you about your operation. Before your operation you will see a doctor from your gynaecology team.

Please let us know if you are taking any regular medicines (including anything you buy yourself over the counter or any herbal or homeopathic medicines) and if you have any allergies.

If you are taking antiplatelet medicines (such as aspirin or clopidogrel) or any anticoagulant medicines (such as warfarin or rivaroxaban), then you may need to stop them in the short term before your surgery. We will review your medicines when you come in for your pre-assessment visit, and will let you know whether you need to make any changes before coming into hospital. Please ask us if you have any questions.

Before your operation you will meet the following:

- Your gynaecology oncology doctor.
- Your clinical nurse specialist who will be your key worker, to give you support and information.
- The stoma nurse specialists to prepare you (physically and psychologically) for having a colostomy, ileal conduit or urinary diversion.
- A counsellor to discuss how you feel about the surgery and possible coping methods (this is optional but you can be referred if you would like). All of these appointments will be before your operation.

What happens during my operation?

You will be given a general anaesthetic, which means that you will be asleep for the whole time of your surgery. Usually, an epidural anaesthetic is used as well so that we can offer you pain relief following your operation to make you more comfortable.

The operation is carried out through a long downward cut. The inside of your tummy is examined to make sure that the cancer has not spread. Sometimes biopsies (small pieces of tissue and lymph glands) are taken and sent immediately to the pathologist, who will look at them to assess how far the cancer has spread. If the cancer has spread beyond what can be removed, the operation is stopped and the cut is closed without doing any more surgery. Otherwise, the operation will be carried out as planned.

Several doctors are involved in your operation, including:

- a gynaecological cancer doctor
- occasionally a urologist
- an anaesthetist

The length of the surgery varies from patient to patient, but it can take between eight and twelve hours to complete.

Will I have to wear a bag ?

If your **bowel** is removed you will need to wear a bag to collect your bowel motions. This may be a permanent stoma, but on some occasions this can be reversed. Sometimes the bowel can be reconnected at the time of the surgery. Your doctor will discuss options with you.

If your **bladder** is removed, you may have to wear a bag to collect your pee. It may be possible to create a continent pouch (a channel connecting part of your small intestine to the wall of your abdomen) which you would need to drain with a tube. Your doctors will discuss these options with you.

What happens after my operation?

The following information is a guide to what may happen after your operation. Everyone recovers at a different pace, but if you have any concerns, please talk to your doctors or nurses. When you wake up you will have:

- an oxygen mask on your face to help you breathe after the general anaesthetic.
- a drip in your arm to give you fluids.
- a small clip on your finger to check your oxygen levels.
- a catheter to drain pee from your bladder.
- one or more drains coming from your wound.

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- a drip in your arm to give you fluids.
- a small clip on your finger to check your oxygen levels.
- a catheter to drain urine from your bladder.
- one or more drains coming from your wound.

You may also have:

- a fine tube down your nose which goes into your stomach. This is called a nasogastric tube and removes any fluids in your stomach so that you don't feel sick.

Depending on your operation, you may have:

- a colostomy with a bag over it to collect bowel motions.
- another bag on your abdomen collecting urine.

You might have a pain-relieving pump. There are two types:

- an epidural pump, which delivers painkillers into your back to desensitise the pain nerves (this may make your legs feel heavy and numb, for a short time); or
- a PCA (patient controlled analgesia) pump, which delivers a dose of painkillers into your vein whenever you press a button, allowing you to control when you receive a dose. Your nurse will explain how to use this pump.

The anaesthetist will discuss these options with you in more detail before you have your operation.

You will feel very tired and it is important that you do not have too many visitors in the first few days after your operation. The nursing staff will help you if you need anything.

You will stay in the intensive care or high dependency unit following your operation so that you can be closely watched and have one-to-one nursing care. When you are stable you will be transferred back to the ward.

On the day after your operation, in order to help you recover, the ward team will encourage you to:

- sit upright, especially out of bed. This lets your lungs open up fully, makes it easier to cough and helps to prevent you getting a chest infection.
- start moving around as soon as possible. This is good for your blood circulation and, along with your anti-embolic stockings, can help prevent blood clots (deep vein thrombosis or DVT).

Please do not get out of bed until your nurse has told you it is safe to do so.

After the operation, it can take a little while for your gut to start working again. This means you will begin by drinking small sips of water.

What happens after my operation?

It is important that you stop smoking for at least 24 hours before your operation, or as soon as possible, to reduce the risk of chest problems. Smoking can also delay wound healing because it reduces the amount of oxygen that goes to the tissues. You can speak to your GP about referring you to a smoking cessation clinic.

What happens whilst I am in hospital?

Each day you will be encouraged to move around (mobilise) more and to become more independent. Your physiotherapist will show you the easiest way to start moving again and will show you some gentle exercises that will help you to regain your fitness level.

You may see an occupational therapist who will check that you will be able to adapt to your normal life following your operation and assess whether anything in your home needs to be modified to help you cope.

Once you are able to drink normally, your drip will be taken down. Drinking plenty of fluids and walking around will also help your bowels to start working again. You will be given oral medicines (taken by mouth) to control any pain and your painkilling pump will be stopped.

Your catheter will also be removed. In the days after your operation, and perhaps for some time afterwards, it is likely that you will feel low, or have difficulty coming to terms with the operation and the changes to your body. This can be caused by the hormonal changes in your body, the anaesthetic you were given, or your feelings about the operation in general. How long these feelings will last varies from woman to woman. Please do not hesitate to talk to your nurse or doctor about how you are feeling.

The nurse specialists will also be available to see you either on the ward or, once you are at home, by phone.

The stoma nurses will see you after your operation and during your inpatient stay, and will teach you how to look after your stoma(s).

They will order stoma bags for you and arrange for a stoma nurse to support you at home. Alternatively, they may arrange for you to visit them in hospital after you have been discharged. They will also give you emergency contact details to use if you have any problems with your stoma once you are discharged.

Advice for when you get home

Below are some guidelines to give you an idea of how much you can do at home.

In the first two weeks after your operation, you will not be able to do much, but you should get out of bed and walk around during the day. You may need to spend your time alternating between rest and activity.

Weeks three to six

You should continue to gently increase the amount of physical activity you are doing - walking is good.

Advice for when you get home

How you recover and what you can do will depend on which operation you have had. Generally it is advisable not to do house work or lift shopping bags for at least six weeks after surgery.

- If you have a vagina, it is advisable that you do not have intercourse for at least six weeks, or until you have been examined by the surgeon.
- Allow for rest time in your daily routine.
- At six weeks, if you are feeling recovered, you can start to drive again.
- You can also return to your normal, everyday activities.

Some women tell us that it can take up to four to six months before they feel fully recovered after an exenteration, but it is different for everyone.

What should I do if I have a problem?

If you have any of the following symptoms, you should contact your GP immediately. If your GP is closed please contact the emergency number your surgery gives you.

You can contact your key worker (nurse specialist) on:

0116 258 4840.

Symptoms to look out for:

- A temperature of 38°C or above (100.4°Fahrenheit).
- Severe pain or increasing pain
- Nausea and vomiting
- Increased bleeding from your vagina (bright red blood or clots)
- Offensive smelling, itchy, yellow/green discharge from your vagina
- Burning pain or discomfort when passing urine
- Unable to pass urine either from the stoma or the continent pouch
- Constipation which lasts longer than three or four days and does not get better after taking a laxative medicine
- Wound pain, or swelling/redness of your wound area
- Discharge (pus) from your wound
- Your wound opening or any of your wounds breaking down
- Pain, swelling or redness in your calf
- A sudden feeling of shortness of breath and/or chest pain

Some common questions

Will my life be different with a stoma to pass pee through (ileal conduit or urostomy) and/or stoma to pass bowel motion through?

Your life will be different and it will take some adjusting to. Your health care team will be here to support you and your nurse specialist (key worker) is available to talk to you (contact number is at the end of this booklet).

If you have met the counsellor before surgery and during your hospital stay, you will have the opportunity to continue seeing this counsellor to help you adapt to life after the operation if this is helpful to you. If you have not met the counsellor, you can be referred after your operation. You can also talk to your key worker or stoma nurse about how you are feeling

Will my life be different now that I don't have a vagina?

Your life will be different now that you do not have a vagina, and this will take some getting used to. You will have discussed your options with your consultant before your operation. You will be able to discuss this with your health care team.

Do I still need to have smear test?

If you have had pelvic radiotherapy already you will not have been having cervical smears. After an exenteration where the uterus (womb) and cervix (neck of the womb) and possibly the vagina (either partial or total) have been removed, it will not be necessary to have smear tests.

Will I be able to have sex?

Usually during pelvic exenteration, most of the vagina is removed.

Your key worker will be available to discuss your concerns and we are able to refer you to a psycho-sexual counsellor if you wish to have on-going support.

Contact number**Gynaecology-oncology nurse specialists (key workers)**

Telephone: 0116 258 4840 (8:00am to 4:00pm)

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk