

Pelvic exenteration in women

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Pelvic exenteration

Pelvic exenteration is an operation that's sometimes used to treat cancer in the pelvis (the area of the body between the hips). This information explains what the operation involves and how you might feel afterwards.

Pelvic exenteration involves removing the bladder and/or part of the lower bowel (rectum), and the internal reproductive organs (the ovaries, womb, cervix and vagina). This operation is only done if there are no signs of cancer anywhere else in the body.

Only specialist surgeons, who are trained and experienced in doing this type of surgery, should carry out pelvic exenteration. So, you may need to be referred to a specialist centre for the operation. Before making the decision to go ahead with any surgery, it's important to discuss the benefits and risks with your surgeon. This is a major operation, but can cure the cancer in some people.

Before the operation, you will be referred to a specialist cancer nurse who will give you information and emotional support. In some units, the specialist nurse may be called your key worker.

When pelvic exenteration is done

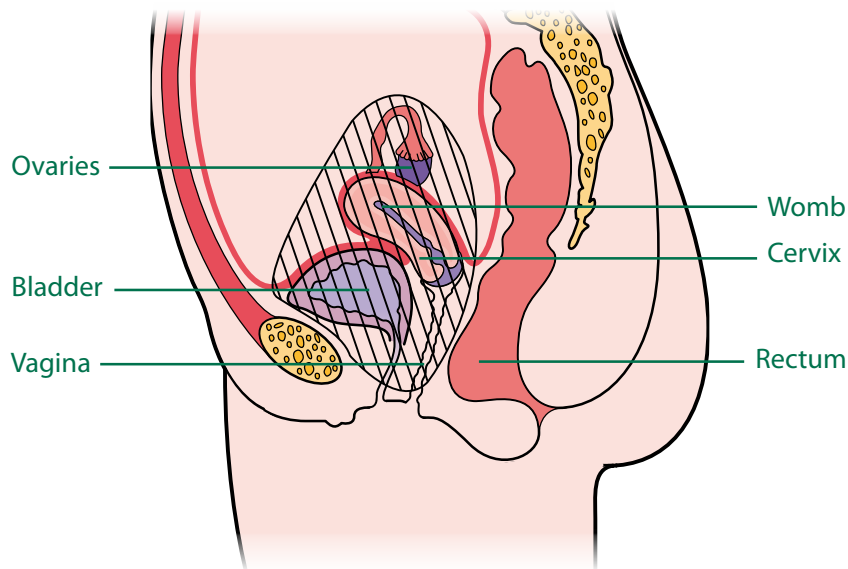
This operation is most often used to treat women who have cervical cancer that has come back in the pelvis after treatment. It may also be used to treat rectal, womb, vaginal or vulval cancers that have come back in the pelvis after treatment. Rarely, pelvic exenteration may be used to treat other cancers in the pelvis.

Types of pelvic exenteration operation

There are different types of pelvic exenteration. The operation you have depends on the type of cancer, where the cancer is in your pelvis, and what treatments you've had before. One of the following operations may be done.

Anterior exenteration (removing organs in the front part of the pelvis)

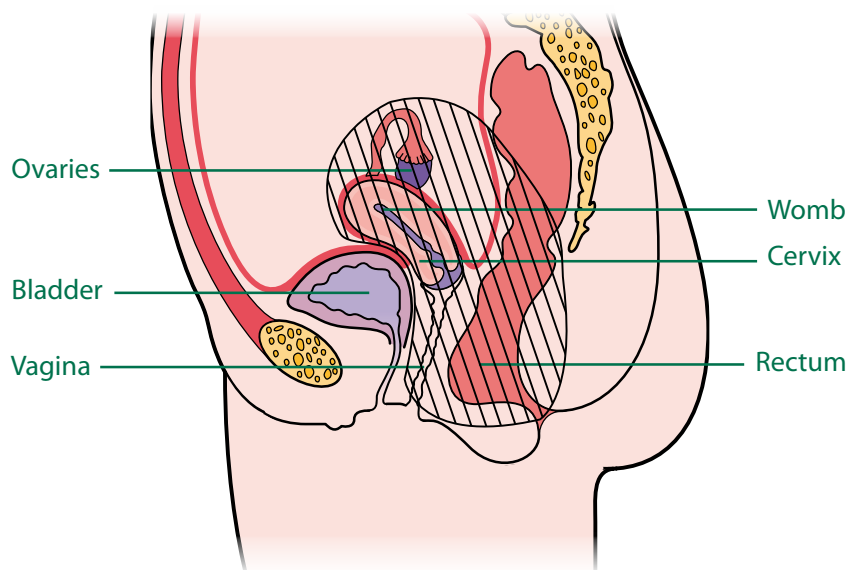
In this operation, the bladder and internal reproductive organs are removed. After the bladder is removed, you'll need a new place for urine to leave your body. The surgeon will make a new opening (a stoma) on your tummy wall for this, called a urostomy.



(Illustration showing the female pelvic organs. The areas removed during anterior pelvic exenteration are shaded over.)

Posterior exenteration (removing organs in the back part of the pelvis)

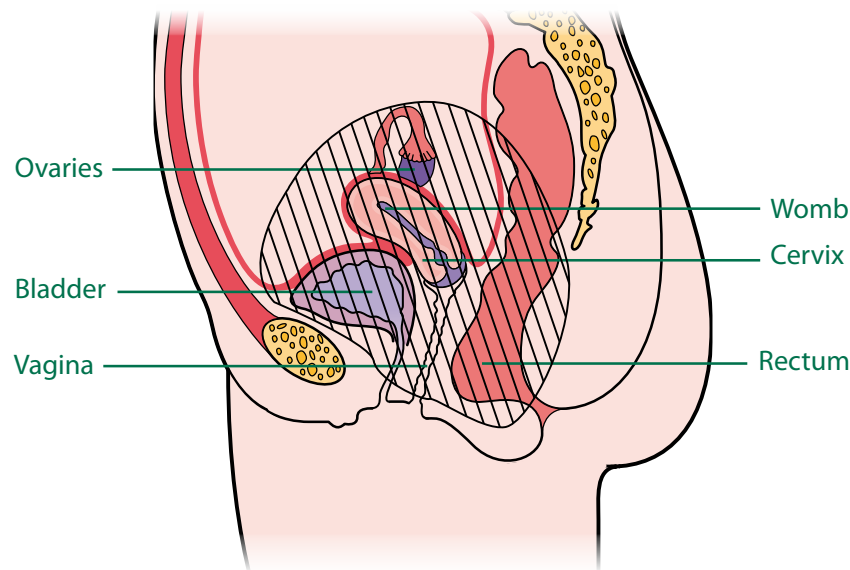
In this operation, the lower part of the large bowel (rectum) and internal reproductive organs are removed. The surgeon will make a new opening (stoma) on the tummy wall for bowel motions to leave the body. This is called a colostomy. You'll wear a bag over the stoma to collect your bowel motions.



(Illustration showing the female pelvic organs. The areas removed during posterior pelvic exenteration are shaded over.)

Total exenteration (removing all the organs in the pelvis)

In this operation, the bladder, rectum and internal reproductive organs are removed. After the operation, you'll have two new openings (stomas) on your tummy wall. One of these will be a new place for urine to leave your body, called a urostomy. The other will be a new place for bowel motions to leave your body, called a colostomy.



(Illustration showing the female pelvic organs. The areas removed during total pelvic exenteration are shaded over.)

Before the operation

Pelvic exenteration is a big operation that isn't possible for everyone. You'll need tests to make sure you're fit enough to have the operation, and you'll need to understand how the operation will change your sex life and the way you go to the toilet.

Preparing for pelvic exenteration

Finding out about the operation

Pelvic exenteration is a big operation that will mean changes to your sex life and how you go to the toilet.

Recovery afterwards can be difficult, both physically and emotionally. To help you make an informed decision about whether to go ahead with the operation, it's important you understand what's involved. Your surgeon or specialist nurse can explain the operation to you and support you in deciding whether it's right for you. It can be helpful to involve your partner (if you have one) or someone close to you in these discussions, so they can support you in your decision.

It can also be helpful to talk to someone who has had the operation. Your surgeon or specialist nurse may be able to arrange this for you. Some support organisations (see pages 10–11) may also be able to put you in touch with someone who has had similar surgery.

Physical preparation

Pelvic exenteration is only possible for a small number of people. Before having the operation, you will have investigations and scans to make sure it's suitable for you.

For a cure to be possible, the cancer needs to be contained in the pelvis. So, your doctors will do tests to look for cancer elsewhere. This usually involves having one or more scans and possibly other tests. If any cancer is found outside the pelvis, the operation wouldn't be successful and so won't be done.

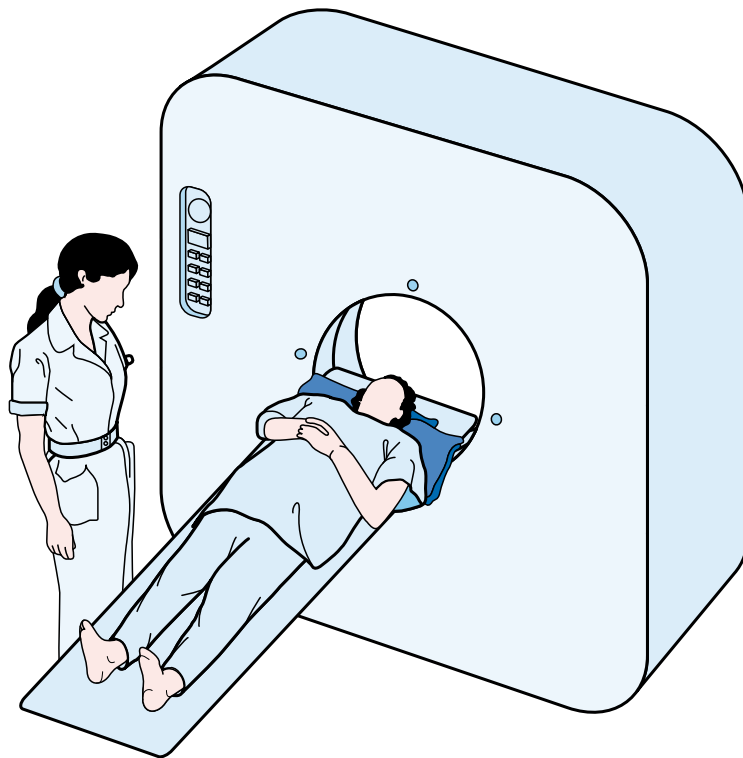
Your doctors also need to make sure you're physically able to cope with the operation and it isn't too risky for you. You may have tests, such as heart and lung tests, to check your general health and fitness.

If you've been having problems with eating and have lost weight, you may be given extra help and support with your diet to help prepare you for the operation. If you smoke, stopping smoking or cutting down before your operation will help reduce the risk of complications after your surgery.

Tests

You may have some of the following tests

CT (computerised tomography) scan A CT scan takes a series of x-rays, which builds up a three-dimensional picture of the inside of your body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and won't harm anyone you come into contact with. You'll be asked not to eat or drink for at least four hours before the scan.



(Someone having a CT scan)

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you're allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the CT scan is over.

PET-CT scan This scan combines a CT scan and a PET (positron emission tomography) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. Sometimes they can show up areas of cancer that may be missed by other scans.

Before you have the scan, you'll have a mildly radioactive liquid injected into a vein, usually in your arm. The radiation dose used is very small. The scan will be done about an hour later and usually takes 30–90 minutes.

MRI (magnetic resonance imaging) scan This scan may be done to help plan the operation. It's similar to a CT scan, but uses magnetism instead of x-rays to build up a detailed picture of areas of your body. It may be done to help the surgeons plan the operation you're going to have.

Before the scan, you'll be asked to remove any metal belongings, including jewellery. Some people are given an injection of dye into a vein in the arm. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll be asked to lie very still on a couch inside a long tube (cylinder) for about 30 minutes. It's painless, but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It's also noisy, but you'll be given earplugs or headphones.

Biopsies If scans or other tests suggest there may be cancer in an area of your body outside your pelvis, you may have samples (biopsies) taken to check. A biopsy is usually taken by putting a fine needle into the area to be tested and withdrawing a sample of cells. This is called a fine needle biopsy or fine needle aspiration (FNA). The sample of cells is then sent to the laboratory to be checked.

This test can generally be done as an outpatient, so you can go home on the same day.

Exploratory/staging operation

Before the pelvic exenteration, an exploratory operation may be needed so your surgeon can look inside your pelvis to check the cancer can be removed with surgery. This is done under a general anaesthetic.

There are two ways in which this can be done: laparoscopy and laparotomy

Laparoscopy This is sometimes called keyhole surgery, as only very small cuts (about 1cm or half an inch long) are made in the tummy. The surgeon puts a thin, flexible tube with a camera on the end (laparoscope) through these cuts. By looking through the laparoscope, the doctor can examine inside the pelvis.

Laparotomy In this operation, the surgeon makes one larger cut in the tummy to examine inside the pelvis.

Going into hospital for pelvic exenteration

If tests show that pelvic exenteration may offer you the chance of a cure, and you decide to go ahead with the operation, you'll be admitted to hospital for the surgery.

A team of specialists will be involved in your care. This team will include surgeons, an anaesthetist (who keeps you asleep during the operation) and specialist nurses. Other people who may be in the team include dietitians, physiotherapists and a counsellor or psychologist.

Before your surgery, the surgeon will come to see you and explain the operation to you, so you have an idea of what to expect in the days following the operation. You'll also see a nurse who specialises in the care of people with stomas (called a stoma nurse). They will explain about stomas and answer any questions you have about them. After the operation, the stoma nurse will teach you how to look after your stomas and give you information and support to help you cope with any problems.

The operation

Pelvic exenteration is a long operation that takes about eight hours. It's usually carried out by two or more surgeons, who work together to remove the cancer and reconstruct or replace some of the organs that are taken away.

The surgeons involved in the operation include a specialist cancer surgeon (oncological surgeon) and a plastic surgeon (reconstructive surgeon).

Depending on the type of pelvic exenteration you have, you may have a urostomy and/or a colostomy made. Some women may also have a new vagina made (vaginal reconstruction).

Urostomy

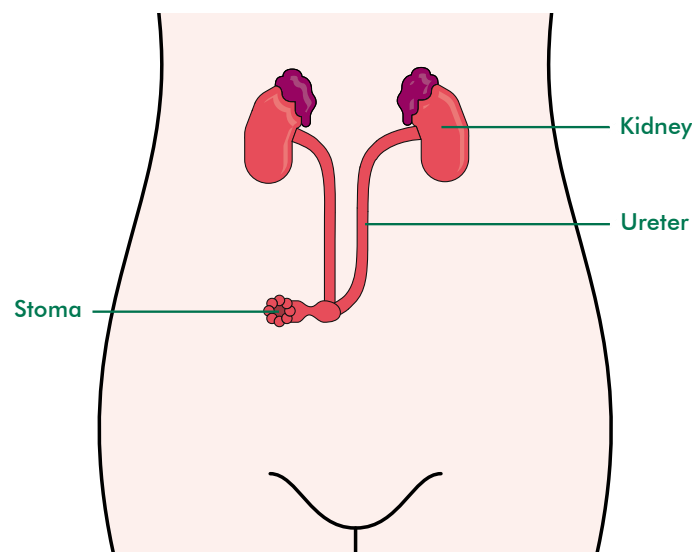
If the bladder is removed, you'll need a new place for urine to leave your body. The surgeon will make a new opening (stoma) on your tummy wall for this, called a urostomy.

There are different types of urostomy. Your surgeon will explain which one is most suitable for you.

Ileal conduit

This is the most common type of urostomy. After the operation, you'll wear an external bag to collect your urine.

The surgeon removes a section of the small bowel and joins the tubes coming from each of the kidneys (ureters) to one end of it. They bring the other open end of the bowel out through a small opening (stoma) in the skin of the tummy wall. Urine made by the kidneys will pass out of the body through this stoma.

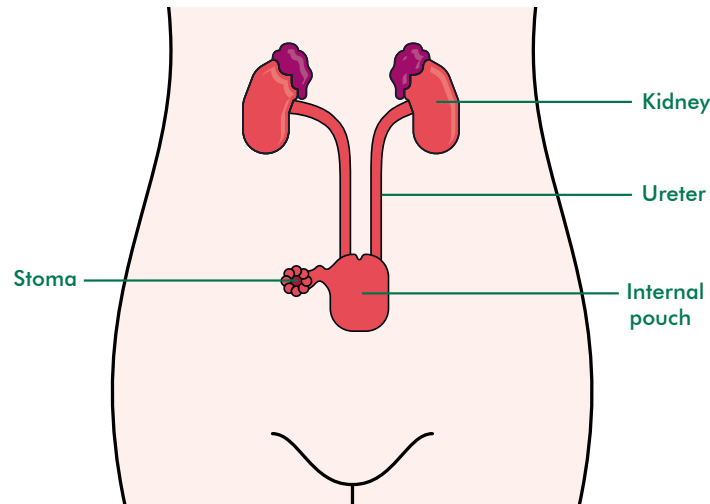


(An ileal conduit)

You'll wear a flat, watertight bag over the stoma to collect your urine. The bag will fill with urine, and you'll need to empty it regularly. Your specialist stoma nurse will show you how to take care of it.

Continent urinary diversion (internal pouch)

With this type of operation, you don't need an external bag to collect your urine. Your surgeon uses a piece of the small bowel to make a pouch that can store urine inside the tummy (abdomen). The pouch is connected to an opening (stoma) on the tummy wall. You empty urine from the pouch by putting a tube (catheter) into the stoma. This is called self-catheterisation.



(A continent urinary diversion (internal pouch))

Colostomy

If the lower part of the bowel (rectum) is removed, the remaining end of the bowel will be brought up to an opening (stoma) on the tummy wall. This is known as a colostomy. You'll wear a bag over the stoma to collect bowel motions. Your specialist stoma nurse will show you how to change the bag and take care of the stoma.

We have an information sheet on living with a stoma, which you may find helpful – call **0808 808 00 00**.

Vaginal reconstruction

This is not always done, but sometimes it may be possible to make a new vagina using tissue from other parts of the body. The surgeon takes a flap of muscle and skin from another part of your body, shapes it into a closed tube and stitches it into place. The blood vessels and nerves for the new vagina stay attached to the place the tissue came from, so the new vagina has feeling. When it heals, the new vagina is like the original in size and shape.

A specialist nurse will give you advice on how to care for a new vagina.

After the operation

You'll be in an intensive care or high-dependency unit for the first few days after the operation, and will probably be in hospital for about 2–3 weeks.

When you wake up after the operation you will have dressings on your tummy. You may also have:

- A drip going into a vein in your arm or neck (intravenous infusion). This will give you food and fluids until you are able to eat and drink again. It may also be used to give you painkillers.
- A fine tube going into your back (epidural). This may be used to give you drugs that numb the nerves and stop you feeling sore.
- A fine tube that passes down your nose, into your stomach or small intestine. This is called a nasogastric tube and it allows any fluids in the stomach to be removed so you don't feel sick. You may need this for a few days.
- One or more drainage tubes coming from your wound to collect any extra fluid or blood. These will be removed when the amount of fluid draining has reduced.
- A bag covering your colostomy.
- A bag covering your urostomy or a tube coming from your urostomy (depending on the type of urostomy).
- If you've had vaginal reconstruction, you will also have drains and bandages on the part of your body from where tissue was taken to make the new vagina.

Pain control

You'll need painkilling drugs for a few weeks after the operation.

To begin with, you'll be given painkillers into a vein (intravenously) or into the space around your spinal cord (epidural anaesthesia). The painkillers are usually given continuously through a pump. The pump may have a hand control with a button you can press to top up your pain control if you feel sore. This is called patient controlled analgesia (PCA). It is designed so you can't give yourself too much painkiller (overdose), so it's okay to press it whenever you're uncomfortable.

It's important to let the doctor or nurses on the ward know if you're in pain, so that the dose can be increased, or the painkillers changed, as soon as possible. When you're ready to go home, your pain will be controlled with tablets and you'll be given a prescription of painkillers to take.

Getting moving

You'll be encouraged to start moving around as soon as possible after the operation. This is an essential part of your recovery. When you're in bed, it's important to do regular leg movements and deep breathing exercises. A physiotherapist or nurse will explain these to you.

A few days after your operation, your nurses will help you get out of bed and sit in a chair. Once all your drips and drains are out, you'll find it easier to move around and take short walks around the ward.

Stomas

After a few days, you'll start being able to do more for yourself. Your stoma nurse will teach you how to change your stoma bags. You may feel worried about doing this to begin with, but most people find they get used to caring for their stoma.

Learning to look after a stoma takes time and patience, and no one expects you to be able to cope straight away. Like anything new, it will get easier with time and practice. We have an information sheet on living with a stoma, which you may find helpful – call **0808 808 00 00**.

Going home

When you go home, you'll need extra help and support for a few weeks as your body heals. If you live alone and don't have anyone who can stay with you, tell the hospital staff so they can arrange help for you.

A district nurse will visit you in your home to help you care for your wound and stomas. You'll also continue to see your stoma nurse. They'll support and advise you while you're learning to care for your stomas.

Recovery from pelvic exenteration takes a long time. It may take about 8–12 weeks after your surgery before you really start to feel better. Build up your activities slowly and only do as much as you feel able to. Your surgeon or nurse will tell you what things to avoid doing until you have had time to heal. As time goes on, you'll begin to feel stronger and have more energy.

How long it takes you to return to work depends on the type of job you do. Ask your surgeon if you're unsure how much time off you'll need. Many people don't feel completely healed for up to six months after surgery, and it can take a year or more to fully adjust. We have a booklet about work and cancer, which you may find useful. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Sexuality

The physical changes to your body after the operation will mean changes to your sex life. You'll need to make both physical and emotional adjustments. The operation varies from person to person, and the effects it has on sexuality will also vary. Your surgeon and specialist nurse will talk you through the changes you may experience.

Although the vagina is removed during pelvic exenteration, the clitoris (through which women have orgasms) usually remains, and many women can still have pleasure from being touched in this area.

If you've had a vaginal reconstruction, sexual intercourse will be possible once you've healed. But you may need to try different positions to find what feels most comfortable for you. You'll also need to use lubricant gels before sex because the new vagina won't make its own lubrication. Your specialist nurse can tell you about these and can give you advice on coping with any difficulties you may have.

We have a booklet about cancer and sexuality. To order it, call us or visit **be.macmillan.org.uk**

Many people have worries and concerns about sex when they first have a stoma. Your stoma nurse will have experience of helping people through this and will be able to give you advice and support. Stoma support organisations also produce information you may find helpful.

Adjusting to changes in how your body looks and responds takes time. Many people need to talk through their feelings and emotions. Some feel nervous about how their partner will react to their body. There is no right or wrong time, or way, to talk about these issues. You can wait until you and your partner feel ready. You may want to consider seeing a sex therapist or counsellor. Your GP or specialist nurse or doctor can refer you. There are also a number of organisations (see below) that can give you information, advice and support about relationships and sexual intimacy.

Your feelings

You may experience many different emotions, including anger, resentment, guilt, anxiety and fear. These are all normal reactions and are part of the process people go through in trying to come to terms with major surgery and with the uncertainty cancer brings. It's important to remember that many people who have pelvic exenteration are cured of cancer and go on to live full and satisfying lives.

Talking about your emotions isn't always easy, but it can help reduce feelings of stress, anxiety and isolation. Try to let your family and friends know how you're feeling so they can support you.

Online support

Many people get support through the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to ask questions and share your experience.

Our online community is a social networking site where you can talk to people in chat rooms, blog your journey, make friendships and join support groups – visit community.macmillan.org.uk

Specialist help

Sometimes it's easier to talk to someone who is not directly involved with your illness. You could ask your hospital consultant or GP to refer you to a doctor or counsellor. Some counsellors are specialists in the emotional problems of people with cancer and their relatives.

Our cancer support specialists can tell you more about counselling and let you know about services in your area – call them on **0808 808 00 00**.

Further resources

Useful organisations

Bladder and Bowel Foundation

The Bladder and Bowel Foundation is a UK charity that provides help, information and advice for all types of bladder and bowel related problems.

Bowel Cancer UK

Bowel Cancer UK raises awareness of bowel cancer, campaigns for best treatment and care, and provides practical support, advice and information about bowel cancer.

British Association for Counselling and Psychotherapy (BACP)

BACP aims to promote awareness and availability of counselling, and to signpost people to appropriate services. The website has a database where you can search for a qualified counsellor.

The College of Sexual and Relationship Therapists (COSRT)

COSRT is a national specialist charity for sex and relationship therapy. It has a list of qualified practitioners and clinics providing sex or relationship therapy in the UK.

Colostomy Association

The Colostomy Association provides support and advice to people who have a colostomy, their family and carers. It produces a range of free literature giving practical guidance. Also offers home and hospital visits by experienced colostomates and a telephone helpline and email service.

Gynae C

Gynae C is a national helpline offering support to women with gynaecological cancer.

Jo's Cervical Cancer Trust

Jo's Cervical Cancer Trust provides information and support for women affected by cervical cancer and their families.

Relate

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support – face-to-face, by phone and through the website.

The Sexual Advice Association

The Sexual Advice Association is a charity that aims to improve people's sexual health and wellbeing, and to raise awareness of how sexual conditions affect the general population.

The Urostomy Association

The Urostomy Association is a self-help organisation that runs a network of groups throughout the country. They can arrange for someone who has had a urostomy to visit you before and after your surgery.

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This information has been compiled using a number of reliable sources including:

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