

Urology department

Total pelvic clearance for women

Introduction

This booklet provides information about your operation. The Christie has a specialised surgical team to treat your cancer.

Please do not hesitate to ask any questions that you or your family may have, and we will do our best to answer them.



What is a total pelvic clearance and why is it necessary?

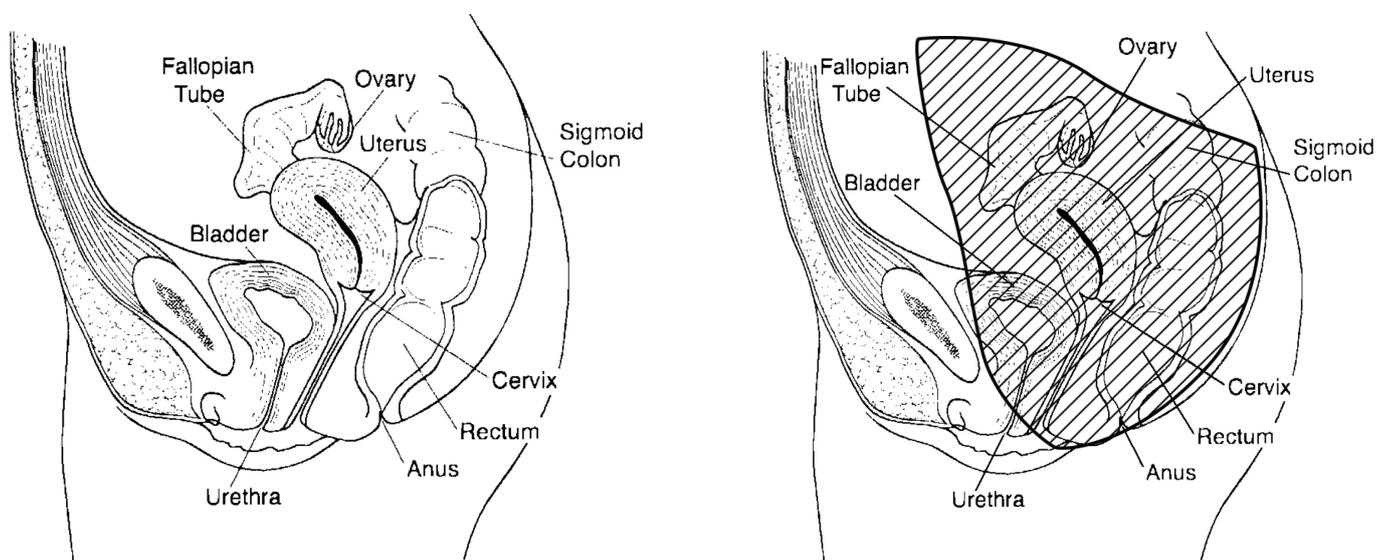
After discussion between you and your consultant's team, it has been agreed that a pelvic clearance is needed to treat your cancer.

A total pelvic clearance is the medical term for removal of your bladder and the lower bowel along with other organs in the pelvis. You may also hear it called a pelvic exenteration. The organs that are removed can involve some or all of the following: your bladder, uterus (womb), ovaries, all or part of your vagina, part of your bowel and your back passage (rectum and anus).

It is important that you feel you understand what is going to happen during the operation, and that you understand which organs are to be removed, before any surgery is carried out.

The first diagram below shows the female pelvic organs and the shaded area in the second diagram shows the organs which will be removed.

Female pelvic organs



How is a total pelvic clearance performed?

To carry out the operation, an incision (cut) will be made in the middle of your abdomen from the belly button to the top of the pubic bone. Occasionally it may also be necessary to make a second incision around the anal area to help with carrying out the operation. The organs affected by the cancer are then removed. Once your bladder and lower bowel are removed, you will have two permanent openings (stomas) created on your abdominal wall to divert and drain your urine and faeces into bags (Please see pages 4 to 5 for stoma information).

In some cases, when a second incision around the anus is made, some of the skin and soft tissue will need to be removed at that time. Usually a plastic surgeon would be involved in the operation to repair the changes made by the surgery. The plastic surgeon may use what is known as a 'flap' to make the repair.

The team looking after you will answer any questions you have about the treatment and its effects.

Agreeing to treatment

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

Benefits and risks of surgery

Benefits of surgery

The intended benefits of surgery are to remove the cancer and to relieve any symptoms you may be experiencing as a result of the cancer. The long-term benefits depend on the extent to which the cancer can be removed.

What happens if I do not have surgery?

If you decide not to have surgery, the cancer will continue to grow and your symptoms may get worse. The team will discuss this with you, and if appropriate will discuss other treatments that may be suitable for you such as chemotherapy.

Are there any alternatives to an operation?

Yes, but these vary from patient to patient. Surgery is thought to be the best form of treatment to remove this type of cancer. However, if you decide not to go ahead with surgery, chemotherapy may be suitable for you. Alternatively, you could opt for a 'watch and wait' policy; this involves deciding on a treatment plan for controlling your symptoms. The team will discuss with you the best form of treatment for you.

Common risks of surgery

This is a major operation and, as with any form of surgery, problems can occur. Common risks of surgery include:

- chest infection (particularly if you are a smoker)
- wound infection
- urine infection
- bleeding and the need for a blood transfusion
- blood clot in the leg (DVT or deep vein thrombosis)
- frequently the bowels can be slow to start working again. This requires patience but usually resolves in time (this is known as an ileus).

We will take steps to minimise the risks of surgery such as giving you TEDs (thromboembolic deterrent stockings) which are special elastic stockings to wear, and giving you blood-thinning injections to prevent DVT.

Less common risks of surgery include:

- post operative bleeding (haemorrhage)
- heart attack (myocardial infarction)
- blood clot in the chest (pulmonary embolism)
- damage to the spleen which may result in it being removed if it cannot be repaired
- formation of internal scarring (adhesions)
- risks of the wound opening up, wound breakdown or skin flap failure
- incomplete removal of the cancer or none of the cancer being removable.

How will total pelvic clearance surgery affect me?

Stoma formation

As your bladder and lower bowel (colon) are removed during surgery, you will no longer be able to sit on the toilet to pass urine and faeces in the usual way. During your operation your surgeon will create two stomas, one for your faeces and wind (colostomy) and a second for your urine (urostomy). The word stoma comes from the Greek, meaning mouth or opening. It is moist, pinky red in colour, and similar to the inside of your mouth. The stoma itself has no feeling, but has a good blood supply, and will protrude slightly on the surface on your abdomen to allow the drainage of waste (urine and faeces) into a bag.

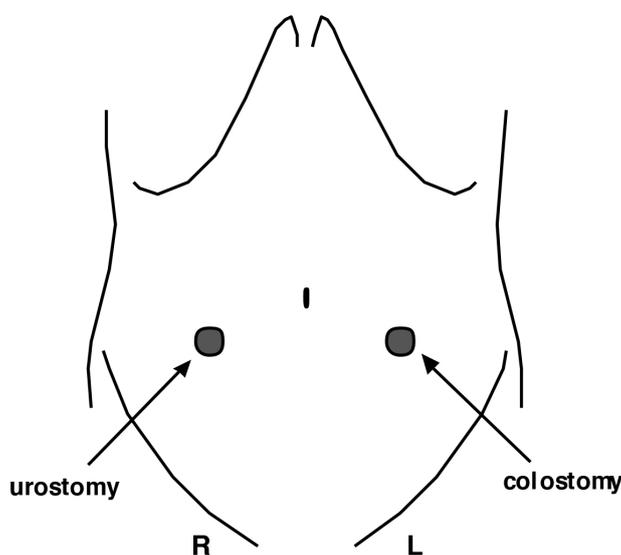
Colostomy

Part of your bowel (colon and rectum) will be removed during your operation, and the upper end will be brought out on to the skin surface to create your colostomy. A colostomy is usually on the left hand side of your abdomen. A bag sticks over the colostomy to collect your faeces and wind. The remaining lower end of your bowel may need to be removed, and if so your back passage will be stitched closed. If this is not necessary the remaining bowel will be closed off, leaving your back passage in place. You may then occasionally feel the urge to go to the toilet as you did before, and may occasionally pass mucus/slime into the toilet. This is normal and nothing to be worried about.

Urostomy

The tubes that carry urine from your kidneys to your bladder (ureters) are disconnected from your bladder and joined to a short piece of your bowel. Usually the small bowel is used but occasionally the colon can be used. This is then brought out onto the skin surface to create your urostomy. A urostomy is usually on the right hand side of your abdomen. A watertight bag with a drainable tap sticks over the urostomy to collect your urine.

The diagram below shows where the stomas will be on the abdomen.



The stoma care nurse specialist will contact you before your admission to hospital to give you more detailed information, including booklets about living with a stoma. You will be shown the type of bags you will need, and given contact details for any further information. You will see the stoma care nurse specialist in hospital before your operation to put marks on your abdomen. This acts as a guide for the surgeon. It is important to do this when you are awake so you are involved in identifying the most suitable place for your stomas.

Following your surgery, the stoma care nurse specialist will continue to see and advise you. She/he will support you until you feel you are able to look after your stomas with confidence. You will be given a supply of bags for your discharge home. The NHS will provide all the necessary appliances for you, and you will be exempt from prescription charges. When you are ready for discharge, we will refer you to a local stoma care nurse specialist who will visit you soon afterwards at home. The stoma care nurse specialist will continue to support you and your family on a practical and emotional level.

We understand that this is a confusing and worrying time for you and your loved ones, and it can be particularly traumatic to learn that your bodily functions will not be the same after your operation. Whatever your reactions and feelings, there are people who you can talk to at The Christie. There is also a network of patients who have had this type of surgery, and are willing to share their experiences and answer any questions you may have, to help you get back to a full active life.

Altered body image

Changes in bodily function and having stomas may affect how you see yourself and how you feel about your body. It is important that you talk to members of your team about any aspects you find difficult to cope with. We are here to help support you and offer advice about any issues you or your loved ones find difficult to come to terms with.

Sexual function and sexuality

A cancer diagnosis can be very emotional and frightening. Often the symptoms you may initially have can affect the way you feel about yourself. If you are currently in a relationship, these reactions may cause a loss in sexual desire. This can be a worrying time for both you and your partner.

Following this type of surgery, as well as having two stomas formed, you may have your uterus (womb) and ovaries removed, as well as part or all of your vagina. This is so that the surgeons can aim to remove all the cancer. The surgery can also interfere with the nerve supply to your genitalia, and may affect your ability to achieve an orgasm. This may have an impact on your sexuality, and also on your sexual function.

Removal of your uterus (womb) and ovaries will mean a loss in fertility and your ability to have children. Removal of these organs will also mean that you stop your menstrual cycle and will start the menopause. This will have been discussed in detail with you before your operation.

If you have consented to have part or all of your vagina removed, and you strongly wish to remain sexually active, please ensure that you discuss these issues with members of your team. There may be a possibility in certain circumstances of making a new vagina in the future using other tissues in your body. All aspects of this type of surgery, and potential results will need to be discussed carefully.

If you are currently in a relationship, this can be a worrying time for your partner also. He or she should be encouraged to be involved in discussions about the operation and how it is likely to affect your relationship afterwards. There are alternative ways to achieve sexual pleasure, and you may need sexual rehabilitation following this type of surgery to explore these issues. At the end of this booklet there are some useful website addresses and telephone numbers you may wish to contact for help and advice.

Before your operation – what to expect

Before your operation you will attend a pre-admission clinic to check a number of things in preparation for surgery.

You will have a MRSA (Methicillin Resistant Staphylococcus Aureus) test before admission to help your team and the nurses plan your care. This involves taking a simple swab of your nose, throat and perineum (seat area). This is a routine procedure carried out on all patients who are admitted to The Christie for surgery. You can get more detailed information on MRSA from the infection control team, or ask one of the nurses.

Other investigations to prepare you for the operation include blood, heart and lung tests. These tests will help us assess your fitness for surgery. Before your operation members of the team will visit you. These include surgeons, anaesthetists, junior doctors, surgical nurse practitioners, and specialist nurses including a stoma care nurse specialist. When you feel you fully understand the operation and what is going to happen to you, we will ask you to sign a consent form. This allows the surgeons to perform the operation you have agreed to.

You will be admitted to the surgical oncology ward the day before your operation, for a stay of approximately 14 to 21 days. The staff will give you bowel preparation to empty your bowel. You will be able to have 'clear fluids', for example black tea/coffee and squash, and we will encourage you to drink plenty of water. If you are unsure of what you can drink, please ask a member of the nursing staff. On the evening before your operation a fluid drip, given through a vein, is put up to help keep you hydrated before your operation.

The nursing staff on the ward will do their best to tell you the time of your operation. The nurses will also tell you when to stop drinking in preparation of surgery. On the morning of your operation you will be asked to have a wash and get ready for theatre. Once you are ready, a nurse will accompany you to the operating theatre.

After your operation – what to expect

Oncology Critical Care Unit (OCCU)

Following your surgery you will be cared for in the OCCU. While you are in the OCCU, you will be awake but under careful observation. You will see equipment that delivers drugs and monitors that display information about your blood pressure, heart rate and rhythm. The machines can be noisy, but please do not be worried since you are being continually observed.

Nursing in the OCCU is usually on a ratio of 1 nurse to 2 patients, to provide the best support. The team will review you on a regular basis and when everything is stable, you will be transferred back to the main ward (surgical oncology ward). The nurses will co-ordinate this and keep you and your family informed.

Pain relief

The anaesthetist will discuss your pain management with you before your operation. The 2 main pain relief options are an epidural (given via a fine tube inserted into your back) or a patient controlled analgesia (PCA is a painkiller via a drip into your vein). There is more detailed written information available; please ask a member of staff or you can download the information on the website: www.christie.nhs.uk

A specialist pain nurse will review the best pain relief to help minimise any discomfort. By the time you are ready to leave hospital, simple painkilling tablets are effective, and they will be provided for you on discharge.

General care

After surgery, you will have a number of drips in place for fluids and drugs. These will be given to you through a vein. Following pelvic surgery, it can take time for bowel function to return (usually 5 to 7 days after the operation, sometimes longer). Throughout the period that your bowel is resting and recovering a drip (IV fluids) will be used to keep you hydrated. You can take sips of water to keep your mouth moist and comfortable.

Sometimes it may take longer for your bowel to recover, in which case liquid food (parenteral nutrition) will be provided through a drip. This is done routinely. The doctors will examine you each day. Once bowel activity shows signs of returning, you will be able to increase the fluids you take by mouth. This will gradually increase until you can manage a light diet.

To help prevent you feeling sick a tube is placed in your stomach via the nose to drain any fluid in the stomach. This is called a nasogastric tube and is placed whilst you are asleep in theatre. It should not affect your ability to talk or breathe and will be removed once you are drinking.

Your abdominal wound is joined with stitches or staples (metal clips). The stitches are usually dissolvable and do not need to be removed. If you have clips, these are normally removed after 10 to 14 days. The nurses on the ward can do this, or district nurses if you have already returned home. If you have a perineal (back passage) wound, the stitches are usually dissolvable and do not need to be removed. If you have a skin flap, the stitches may not be dissolvable and are normally removed after 10 to 14 days.

When you have had an operation, it is normal for blood and fluid to be produced, so you may have a drain or tube in your abdomen to remove this fluid. The amount will be monitored and the tube will be removed when drainage decreases. Your nurse will remove the drain on the ward. These procedures are not painful, but can be a little uncomfortable. If you are at all worried, talk with the nursing staff.

During your stay on the surgical unit, you will wear stockings called (TEDS). You will receive a daily injection of a blood-thinning agent (anticoagulant). The TED stockings and the injection help prevent blood clots forming in your legs. You will be discharged home with blood thinning injections (anticoagulants) for a period of time as discussed with you by your team (usually for 28 days after your operation).

If you have any questions at any time, ask any member of your team. They will be pleased to explain anything that concerns you or your family. Another good tip is to write your thoughts and questions down so that you do not forget.

Physiotherapy

Physiotherapy early after your operation can reduce the risks of a chest infection as well as preventing blood clots forming in your legs. Physiotherapy will start the day after your operation. The role of the physiotherapist is to work with you to help improve your lungs, and to increase your movement after surgery. Try to move around as soon as you can.

Counselling and psychological support

Patients and relatives may have difficulty in coping with illness, the effects of treatment and the effects of surgery on self-image, and may benefit from counselling and psychological support. As part of your care, your team will be able to discuss any issues or concerns you may have as a result of surgery. If appropriate, and with your consent, we can refer you to a trained counsellor. We have a counsellor and a consultant psycho-oncologist who specialise in problems relating to having a life-threatening disease. Anyone who thinks they may be helped by these services should talk to one of the surgical team, and if appropriate ask to be referred.

Alternatively, the counselling service can be contacted directly on **0161 446 8038**.

Hospital chaplaincy and spiritual needs

Like many people who are ill, you may be trying to make some sense out of what is happening to you. You can talk to members of the chaplaincy team about your concerns whether or not you consider yourself religious. If you would like to speak to one of the chaplaincy team, please ask one of the ward nurses to contact them.

Getting back to normal

Recovery time after surgery varies. You may find it takes weeks, sometimes months, to feel better; however, you can expect a gradual improvement over the next 6 to 12 weeks.

- You should not attempt to drive a car, lift or move heavy objects, start digging the garden or do heavy housework (for example hoovering) until you feel completely comfortable and safe to do so.
- Getting back to work will depend on the type of job you do. Please ask if you are unsure. The ward clerk can give you a sick note for the time that you are in hospital. Your GP can then supply you with any further sick notes.
- Getting back to normal activities and exercise depends on you. It is safe to gently increase your levels of physical activity providing it is comfortable to do so.

Follow-up after surgery

We will see you in The Christie outpatient clinic after your stay in hospital and we will review your progress at regular intervals. On each visit you will have routine blood tests. X-rays and scans of your kidneys will be performed after 3 months, and then yearly. These tests are needed to help the team check that your kidneys are working normally. CT scans will also be done every 6 months, and then yearly to make sure the cancer has not returned. Along with these tests, you will have the opportunity to talk to the team about any concerns you may have. If you have any problems in between visits, use the contact numbers listed at the back of this booklet. Alternatively, contact your GP.

Visitors

Visitors are usually welcome at any time. If your visitor can only visit in the morning please note that medical staff may be seeing patients so they may have to wait if they wish to speak to a doctor. During the early post-operative days we do ask visitors to limit their stay so that you can get enough sleep and rest to help recover from your operation. We recognise that this is a particularly stressful and anxious time for families and friends but your rest is also very important. Telephone enquiries are welcome. We do ask if you come from a large family to nominate a spokesperson so that any information can be passed through that individual to everyone else. This reduces interruptions and gives the staff time to attend to your needs.

Accommodation for relatives

We have some single accommodation located near The Christie for relatives of seriously ill patients who have to travel a distance. For more details, please ring the hospital on **0161 446 3000** and ask for the Accommodation supervisor, or discuss this with the team looking after you.

Who are we?

We are a specialist team dealing with pelvic cancers. The team includes surgeons, doctors, surgical nurse practitioners and other specialist nurses including stoma care nurse specialists. The surgeons that specialise in this type of surgery often work together with other surgeons and doctors both inside the hospital and at other hospitals. As part of the team there will also be junior doctors present who will care for you during your stay at The Christie. As The Christie is a teaching hospital, team members will also include trainee doctors (medical students) and student nurses.

Your consultant is:

Contact number (secretary):

Your specialist nurse is:

Contact number:

Your stoma care nurse specialist is:

Contact number:

Out of hours

If you need urgent medical advice at night or weekends, please contact your GP or ring The Christie switchboard on **0161 446 3000** and ask for the surgical doctor on call.

Further information

Visit the cancer information centre in the main Oak Road reception area (department 3) can give you information about support services and helpful websites. **0161 446 8100**.

The Christie at Oldham: **0161 918 7745**

The Christie at Salford: **0161 918 7804**

Maggie's centres

The centres provides a full programme of practical and emotional support, including psychological support, benefits advice, nutrition and head care workshops, relaxation and stress management.

Maggie's Manchester: Tel: **0161 641 4848** or email manchester@maggiescentres.org

The Robert Parfett Building, 15 Kinnaird Road, Manchester M20 4QL

Maggie's Oldham: Tel: **0161 989 0550** or email oldham@maggiescentres.org

The Sir Norman Stoller Building, The Royal Oldham Hospital, Rochdale Road, Oldham OL2 2JH

Patient Advice and Liaison Service (PALS)

PALS provide a confidential listening, advice, information and support service for any patient, relative or carers who might have problems using Christie services.

Telephone **0161 446 8217** or e-mail pals@christie.nhs.uk

Helpful websites & telephone numbers:

The Christie: www.christie.nhs.uk

Macmillan Cancer Support: www.macmillan.org.uk

Tel: **0808 808 0000**

Bowel Cancer UK: www.bowelcanceruk.org.uk

Tel: **020 7940 1760**

Beating Bowel Cancer: www.beatingbowelcancer.org

Tel: **020 8973 0011**

Bladder and Bowel Foundation: www.bladderandbowel.org

Tel: **0845 345 0165**

College of Sexual Relationship Therapists: www.cosrt.org.uk

Tel: **020 8543 2707**

Urostomy Association www.urostomyassociation.org.uk

Tel: **01889 563191**

Colostomy Association www.colostomyassociation.org.uk

Tel: **0800 328 4257**

Smoking cessation, please contact Complementary therapies at The Christie on **0161 446 7175** or **8236**

Illustrations reproduced with the permission of www.medicalcenter.osu.edu
Copyright the Ohio State University Medical Center, Columbus, Ohio, USA.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.

Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week

