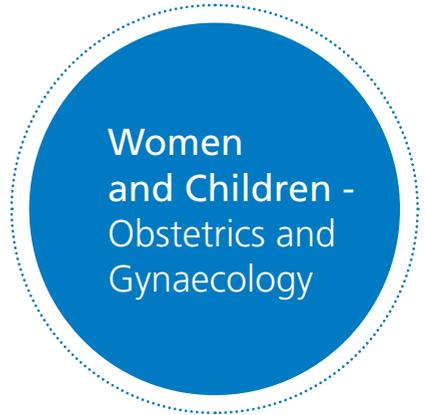


Exenteration

With the Enhanced Recovery Programme

Patient Information



Women
and Children -
Obstetrics and
Gynaecology

Even if your surgeon has explained to you what the operation entails many of us do not take in everything mentioned in the clinic, so this booklet is to help you understand your condition and the reason for the intended treatment.

As we are all different, it is not possible to personalise this information, so there may be differences between your individual case and the information given here.

If you have any queries regarding the information please discuss them with the consultant or a member of his/her team (doctors or nursing staff).

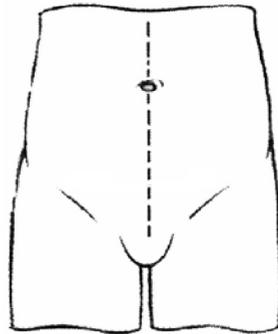
Why do I need exenteration?

The cancer in your pelvis has returned following previous treatment.

What does the operation involve?

A laparotomy incision (cut) is used.

The surgeon opens the abdomen (tummy), starting at the top of the pubic hairline and going up to, and sometimes above, the umbilicus (belly button). You may be having an anterior exenteration, a posterior exenteration or total exenteration.



Anterior (front) exenteration

This will involve removal of the following structures and organs at the front of the pelvis: both ovaries and tubes, uterus (womb), cervix (neck of the womb) and omentum, (a pad of fat shaped rather like a baby's bib) unless these have already been removed.

The vagina and the bladder are removed and an opening is made in the abdominal wall allowing the ureters (the tubes leading from the kidneys to the bladder) to drain directly from the kidneys into a bag placed onto the skin. This opening is known as a urostomy.

Posterior (back) exenteration

This will involve removal of the following structures and organs in the back of the pelvis: The lower part of the large intestine (bowel), the rectum and anus (back passage).

An opening is made in the abdominal wall to open up a section of the large bowel, often called a stoma or colostomy. A colostomy bag is placed over the stoma to collect the waste products that would usually pass through the bowel and out of the body through the rectum and anus.

Total exenteration

This combines both of the above operations. There will be two separate openings on your abdomen for the urostomy and colostomy.

Are there any alternatives to exenteration?

Radiotherapy with, or without, chemotherapy, can be used to relieve the symptoms of the cancer but it only works for short periods of time. The decision you need to make about your treatment is a difficult one but please be assured that if you choose not to have exenteration, there is care and support available.

When we deal with the symptoms that arise from the cancer and do nothing to control the actual disease, it is called “Best Supportive Care” and can involve seeing a consultant specialising in palliative care and having the support of macmillan nurses.

Are there any complications or risks associated with exenteration?

We know there may be complications following various gynaecological operations or procedures, that are not particularly serious but do happen more often.

These frequently occurring risks include: Pain, bruising, delayed wound healing, scarring of the skin or scar tissue inside (adhesions). Numbness, tingling or burning sensation around the scar which may take weeks or months to resolve. Anaemia, fatigue / tiredness. Urinary frequency or loss of control. Wound infection, urinary tract infection or chest infection which is usually easily treated with antibiotics. Patients are encouraged to follow the recommended post-operative breathing exercises and to stop smoking.

Are there any ‘more serious’ risks?

There can be other complications following any gynaecological operation. Whilst these don’t happen often when they do occur they can be serious. It is known some risks are increased if you already have underlying medical problems or if there is scar tissue (from previous operations or disease) which makes the operation more difficult. The risks are also increased if you are obese or if you smoke. The more serious risks include:

1) Infection. This may occur in the pelvis, incision site or in the chest. Infections are usually easily treated with antibiotics but occasionally an abscess may form in the pelvis which may require surgical drainage under anaesthetic. All ladies having exenteration are given antibiotics pre-operatively to help prevent occurrence of infection.

2) Bleeding. This may occur during the operation or, rarely, afterwards and may be enough to need a blood transfusion. If you have had some internal bleeding and we find blood has collected in your pelvis, we call this a haematoma. A haematoma can usually be easily treated with antibiotics, to encourage the blood to drain out through your vagina, but occasionally it may need to be drained surgically under anaesthetic. A haematoma is often described as a blood clot, and this is quite a good description but must not be confused with the blood clots described in section four.

3) Visceral injury. This means injury to the ureters or to the remaining pelvic structures or organs. These complications would usually be found during the operation and dealt with immediately. In rare cases the problem may not become apparent for a few days after the operation and this may require a second laparotomy to resolve the problem.

4) Venous Thromboembolism. There are two types:

Deep vein thrombosis (DVT) ... following a hysterectomy, it is possible for clots of blood to form in the deep veins of the legs and pelvis. If this does occur, a deep vein thrombosis would cause pain and swelling in a leg and can be treated relatively simply with drugs. The risk of developing a DVT is minimal, as many precautions are taken to help prevent and minimise the risks such as: recommending you reduce or stop your smoking in the weeks before your operation, the use of support stockings and/or medication to 'thin the blood', the use of special equipment in the operating theatre and also the recommended post-operative leg exercises.

Pulmonary embolism ... in rare cases, it is possible for a clot to break away and be deposited in the lungs and if this occurs it is a serious situation and will need immediate treatment with drugs. The precautions against pulmonary embolism are the same as for DVT.

4) Death. With any gynaecological operation there is some risk of death but as exenteration is a very complicated and long procedure, sometimes taking over eight hours to perform, the risks are considerably greater than usual. However, the possibility of death is thought to be less than five women in every 100 operations performed.

If you do have any concerns about the risk of complications, please discuss them with the consultant or a member of his/her team (doctors or nursing staff) and your questions will be answered as clearly and as honestly as possible.

What happens before the operation?

For this operation, you will be taking part in an enhanced recovery programme with the aim of helping you recover quickly and safely. During your short stay in hospital there will be goals which you will be encouraged to achieve. A team of doctors, nurses, physiotherapists and other healthcare professionals will be monitoring your progress and will support you in reaching your goals so in most cases you will be asked to attend a pre-admission session shortly before you are due to have your operation. You will be seen by a nurse who will begin your plan of care.

The nurse will also review your medical history. You will have your weight and height, blood pressure and pulse and some blood samples taken. Depending on your age or medical history you might also be requested to attend other departments on the same day for investigations such as an ECG – Electrocardiogram (heart tracing), a lung function test or a chest X-ray. You may also need to see a doctor for a more detailed medical examination. You will need to take all your medicines to pre-admission with you as most should be continued before your operation and throughout your hospital stay but some may need to be stopped to reduce any risks and to avoid your operation being delayed or cancelled. The pre-admission team will advise you and also give you a bag to bring your medicines into hospital.

This is also an opportunity for you to tell us about your own individual needs and circumstances. It is our aim for you to have a speedy recovery and safe discharge so it is important you tell us as early as possible if you have any concerns about whether or not you will be able to manage your daily activities when you go home. You may wish to bring along a relative or close friend to pre-admission who can also be

involved and support you in planning your enhanced recovery. You will have the opportunity to ask the nurse any questions.

Your anaesthetist would prefer you to stop cigarette and cannabis smoking in the weeks before your operation, as this is known to increase the risk of anaesthetic complications, e.g. breathing difficulties, coughing, nausea and sickness and chest infection. On the day before your operation you will be able to eat and drink as normal but please avoid drinking alcohol on the evening before your operation as this may lead to dehydration.

To reduce the possibility of skin infection, we request you do not shave your bikini-line or your legs during the week before your operation but some 'trimming back' of excess pubic hair may be required, you can do this yourself at home or the nursing staff will help you after you are admitted.

A key aspect of the enhanced recovery programme is that you will be given clear carbohydrate drinks before your surgery. These drinks will help to give you the much needed energy which you will require to help you recover so your admission date will be confirmed at pre-assessment, as it may be necessary for you to be admitted the day before your operation.

Admission into hospital

If you are admitted on the day of your operation, please do not eat and drink after on your operation day. Do not suck sweets or chew gum.

You will need to take a bath or shower at home and take off as much of your jewellery as possible although we are able to cover wedding rings/bangles if you are unable to remove them.

If you are admitted the day before your operation, the nursing staff will help and advise you about the above.

To reduce the possibility of any damage to your eyes, it is very important you remove all mascara and wear glasses instead of any type of contact lenses. Please wear comfortable clothes that are not tight around the waist.

You will need to bring a packet of sanitary towels into hospital with you, toiletries, dressing gown, nightgown and slippers, and you may also choose to bring in a book or magazine.

Please be aware that South Tees Hospitals NHS Trust cannot be held responsible for any personal belongings, valuables or money you bring in with you.

Please read your admission letter carefully to see where you are being admitted to. If you are unsure, you may phone the nursing staff as follows:

- **Women's Health Unit at The James Cook University Hospital: 01642 854527**
- **The Surgical Admissions Unit at The James Cook University Hospital: 01642 854603**

What can I expect on the operation day?

If you have not already signed your consent form for the operation, you will be seen by your consultant or a member of his/her team who will explain your operation in detail and answer any questions you may have. You will then be required to sign the consent form. You will also have the chance to speak to your anaesthetist before your operation so that you can discuss any concerns about your anaesthetic. Because of

the extent of the surgery it may be advised that you have a spinal or epidural anaesthetic. This will depend on discussion between you and your anaesthetist. You will still be sedated but a spinal (epidural) may be advised to aid a speedy recovery and pain management. The nurses will give you 'support socks' and a small injection may be given to thin the blood, helping to reduce the risk of a blood clot developing in your legs during the operation. You will then be transferred to the theatre area by a nurse and or porter.

What can I expect after the operation

When the operation is completed you will be woken by the anaesthetist and transferred to the recovery area in theatre. Your recovery nurse will look after you and stay with you until he/she is satisfied with your condition. You will be transferred to the HDU (High Dependency Unit) or the ITU (Intensive Therapy Unit). The staff, with the help of the theatre porter, will transfer you into your bed. You will probably feel drowsy for a quite a few hours afterwards.

To enhance your recovery it is important you start doing the recommended breathing exercises, as described in the back of this booklet, as soon as you wake up.

You are likely to have a 'drip' (also known as an I.V.) to give you intravenous fluids. A few hours after your operation you will be able to start drinking and you may even have something to eat if you are not feeling sick. It is important you eat and drink early after your operation so we will encourage you to have normal food as well as nourishing drinks which will be available for you while you are in hospital.

Effective pain and sickness control is an important part of the enhanced recovery programme as this will allow you to start walking around, breathe deeply, eat and drink, feel relaxed and sleep well. If your pain is too great or if you are feeling too sick to allow you to do any of these activities, please speak to the nursing staff caring for you so your pain control or anti-sickness medication can be reviewed. Pain and sickness may be controlled with a PCAM machine (Patient Controlled Analgesia Monitoring) allowing you to control the amount of pain relief and anti-sickness drugs that you have and should result in a comfortable recovery. If you do use a PCA it will be removed once you are able to tolerate painkillers by mouth, or in suppository form, usually within 24 hours of the operation.

If you have had a posterior (back) exenteration, you may have a catheter inserted into your bladder. This will drain your urine and will remain in place until you are fully mobile and able to pass urine normally.

What can I expect in the days after the operation?

To enhance your recovery you may be visited by the physiotherapist the day after your operation. She will give you advice on gentle post-operative exercise and a leaflet to read.

As soon as the HDU/ITU staff are satisfied with your condition you will be transferred to the women's health unit to continue your care with the gynaecology team.

You will be encouraged to increase your mobility gradually during the days after your operation until you can be fully mobile making it possible for you to have a shower or to go in the bath, with some assistance from the staff.

You may feel much more tired than usual after your operation as your body is using a lot of energy to heal itself so you may need to take a nap for the first few days.

An exenteration can also be emotionally stressful and many women feel tearful and emotional at first – when you are tired these feelings can seem worse. For many women this is often the last symptom to improve.

It usually takes a few days before your bowels, and colostomy if you have one, start to work normally and you may experience discomfort associated with a build-up of wind. This usually resolves itself, but if it becomes a problem the nursing staff may provide some peppermint water to drink and encourage taking gentle exercise. You may want to bring a bottle of baby's gripe water into hospital with you as many women feel that this is effective in relieving wind pain.

It is important to keep your genital area and any abdominal wounds clean. A daily bath or shower is advisable paying particular attention to these areas. Avoid the use of highly scented soaps, bubble bath and vaginal deodorants, etc. We will provide a separate sterile towel to dry the wound and a sterile dressing to cover the wound after bathing. If dressings are still needed on discharge they will be provided by the nursing staff.

You may have dissolving stitches in your wound, in which case you will be advised by the nursing staff how to care for them. If you have clips, staples or stitches (sutures) which need to be removed, the nursing staff will explain how to care for your wound and advise you when they will be removed.

You should expect to have some vaginal bleeding in the first few days after the operation. The bleeding normally turns into a red/brownish discharge before stopping completely and can last anything from a few days to a few weeks. If bleeding becomes heavier than a period or smells very offensive, let the doctor or nursing staff know as it may mean that you have an infection. We advise you to use sanitary towels in preference to tampons whilst the bleeding persists, as this will help you to keep a check on the amount you are losing and will help to reduce the risk of infection associated with tampon use. Some further, slight, bleeding may occur about four to six weeks after your operation. This can happen because your internal stitches are dissolving. As long as this bleeding only lasts for a day or two do not worry, but if it becomes very heavy and you are worried, please contact your GP.

How long can I expect to be in hospital after the operation?

Many patients feel well enough to leave hospital about a week after the operation but you must tell your nurse how you are feeling and she will help you to decide whether you are ready.

Will I get any medication to take home on discharge?

You will take home the medicines you brought in with you. We will provide any extra medicines you may need, such as painkillers or antibiotics, from the hospital pharmacy.

You will require dressings and may need stoma bags, this will also be organised from the ward.

How will my care continue?

After your operation, the tissues taken away will be fully analysed then discussed at our Multidisciplinary Team (MDT) meeting and this may take up to four weeks.

We will have asked you, at pre assessment, how you would like to receive your results, either by a formal visit to the out-patients clinic or by a telephone call from the specialist nurse.

If you have any questions, please ask any of the team looking after you – we are happy to help. You may find it helpful to write down the questions, so that you do not forget them. If you need to contact us, please feel free to do so.

The Cancer Nurse Specialist is happy to speak to you at any time. Her number is 01642 282418. If she is not there, an answerphone is available. If you need to speak to someone urgently, the staff on Ward 27 at The James Cook University Hospital will be happy to help (01642 854527).

If you do not need further treatment we may make arrangements to see you back in the clinic after about two months to make sure that there are no further problems.

You will be followed up in the Gynae/Oncology clinic for five years following your surgery. Follow-up is three monthly, then four monthly, then six monthly, then yearly, but always remember if you have any problems contact your GP.

What happens when I go home?

You will go home wearing the support stockings you were given and are advised to wear them for at least six weeks night and day until you are back to your full mobility.

Following exenteration the rate of recovery depends on each individual and to a large extent on your state of health before the operation. It is important that you resume your normal activities gradually and limit what you do by how tired or uncomfortable you feel.

Continue with any exercises that you were advised to do in hospital. You may find that you get tired quite quickly at first. This is normal and will improve along with your general fitness level.

You can normally resume driving when you can stamp your feet hard on the ground without causing pain or discomfort, and when you believe that your concentration will not be impaired. Your insurance company will probably assume that you are not fit to drive after a major operation until your doctor says you can. If you have any concerns about this, check with your own GP.

Returning to work is up to the individual concerned and depends on the type of job you do. Any job requiring heavy lifting may take a bit longer to return to, usually about 12 weeks, but if you are in a job with no lifting involved, you may be able to return after six to eight weeks but you are the best judge as to how you feel. Remember, however, that you have had a major operation and time is needed to allow the healing of the wounds.

Depending on the extent of the surgery a sex life may not be possible this will depend on what has been removed the medical team will discuss this with you as it can vary vastly between patients.

General advice

If you have any of the following symptoms, you should contact your GP:

- A smelly discharge or bleeding through the vaginal or anal stitches which is heavy and 'fresh' (bright red) or the passing of clots.
- Pain which is severe and not controlled by your prescribed painkillers.
- Feeling unwell, hot and feverish.
- Pain in the calf muscles or chest.

Breathing exercises

The recommended breathing exercises mentioned should help maintain a clear chest, tone up muscles and ease wind pain following surgery. Start this exercise as soon as you wake up from the anaesthetic and do regularly until you increase your walking.

Bend your knees up with feet flat on the bed, breathe in through your nose until your lungs are as full as possible, then relax as you breathe out through your mouth. Repeat five times every half hour or so, and follow with two huffs.

Huff: Position as above with hands or pillows supporting any area of discomfort. Take a medium breath in, then force the air out quickly through an open mouth, as though you are trying to mist up a large mirror. Follow this with a cough – take a big breath in first, and do not worry about this doing any damage in the area of your surgery.

Foot and knee exercises: These should help the circulation and help prevent clots from forming in your legs. Repeat every time you do your breathing exercises and until you are walking about. Bend feet up and down at the ankle firmly and quickly. Draw circles with your feet. Press back of the knees into the bed and tighten up the thigh muscles.

Hospital contact information

The James Cook University Hospital

Appointments Desk: 01642 854861 / 282714 / 854883

Gynaecology Outpatients Department
(including pre-admission service): 01642 854243

Surgical Admissions Unit: 01642 854603

Women's Health Unit (Ward 27): 01642 854527

Useful contacts:

<http://www.macmillan.org.uk/Cancerinformation>

<http://www.cancerresearchuk.org/cancer-help>

The Jo's cervical cancer trust website: www.jostrust.org.uk

The Royal College of Obstetricians and Gynaecologists,
27 Sussex Place, London NW1 4RG.

More patient information is available on their website:
www.rcog.org.uk/womens-health/patient-information



Ova the Rainbow is a support group for anyone who would like support for themselves or their friends and family due to any gynaecological cancer.

Registered charity number 105560061

It was established at the end of 2001 by two specialist oncology nurses, Jane McNeil and Lynne Wright out of the James Cook University Hospital. The Friarage branch was established in 2005 by Maggie Wright.

We are a registered charity and our meetings are held monthly for friends, family and any other supporters.

First Friday of the month,
11am – 1pm
The Trinity Centre,
James Street,
North Ormesby,
Middlesbrough TS3 6LD

For further details please
contact: **01642 282418**

First Tuesday of the month,
2pm – 3:30
Allerton Court Hotel
Darlington Road
Northallerton
North Yorkshire DL6 2XF

For further details please
contact: **01609 764688**

We hope you have found this information helpful.

Please remember our staff will be happy to answer any questions you have about any aspect of your care and welcome any comments about this booklet.

Comments, compliments, concerns or complaints

South Tees Hospitals NHS Foundation Trust is concerned about the quality of care you receive and strives to maintain high standards of health care.

However we do appreciate that there may be an occasion where you, or your family, feel dissatisfied with the standard of service you receive. Please do not hesitate to tell us about your concerns as this helps us to learn from your experience and to improve services for future patients.

Patient Advice and Liaison Service (PALS)

This service aims to advise and support patients, families and carers and help sort out problems quickly on your behalf.

This service is available, and based, at The James Cook University Hospital but also covers the Friarage Hospital in Northallerton, our community hospitals and community health services. Please ask a member of staff for further information.

Authors: The Gynaecology Cancer Nurse Specialist and the Gynaecology Oncology Team

The James Cook University Hospital

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