NGOC
Northern Gynaecological Oncology Centre

NHS
Gateshead Health
NHS Foundation Trust

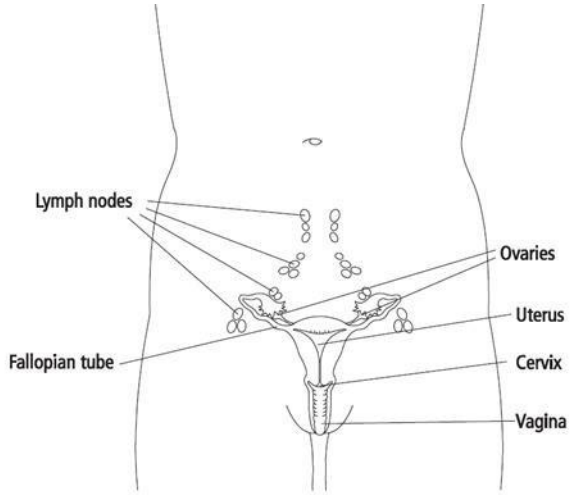
# Hysterectomy for Endometrial Cancer

# Hysterectomy for Endometrial Cancer

This information leaflet provides some general information about your surgery. The information in this leaflet should already have been explained to you by a doctor. We hope that this helps you to remember what you discussed with your doctor, and also to answer any questions that you may have. If you still have questions after reading this leaflet, then please contact a member of your team on one of the telephone numbers at the end of this leaflet.

## What is a hysterectomy?

Following the investigations that you have had, you have been diagnosed with endometrial cancer (cancer of the lining of the womb). Most women with endometrial cancer are treated with surgery to remove the womb and cervix and this is called a hysterectomy. It is also important to remove the fallopian tubes and both ovaries during this surgery.




## Why do I need surgery?

The main reason for surgery is to remove the cancer. For a small number of women who have cancer that has spread outside of the womb, the surgery will allow your doctors to know where it has spread to (this is called staging), and whether any further treatment such as chemotherapy or radiotherapy, is needed.

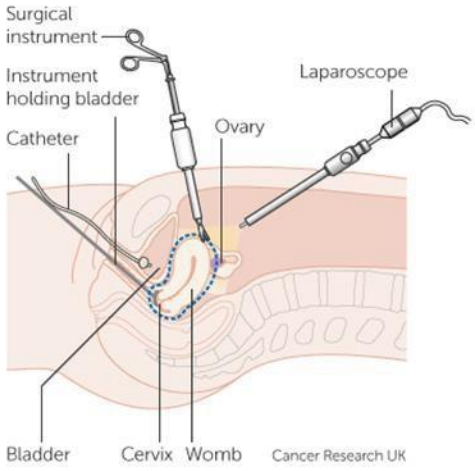
## What if you decide not to have surgery?

Your decision to not have surgery for your cancer will be respected at all times by your doctor. A meeting to discuss any other options can be arranged.

## Why happens during surgery for endometrial cancer?

Surgery for endometrial cancer is usually done through keyhole incisions (laparoscopic surgery). This would involve a laparoscope (keyhole camera) inserted through a small cut under the umbilicus (tummy button). The surgeon makes several other small cuts in the abdomen (tummy) through which the surgical instruments are inserted. The womb (uterus) along with the cervix

(neck of womb), fallopian tubes and ovaries are removed (bilateral salpingo-oophorectomy). Sometimes it is necessary to remove some lymph nodes (glands) in the pelvis. Lymph nodes are tiny structures (usually the size of a pea) that are found throughout the body. They are important in moving fluid around the body. Your surgeon will discuss this with you before your surgery.
They may explain the benefit of removing the first nodes that a cancer would spread to (sentinel nodes), in addition to other nodes.




In some cases the surgeon may have to perform a laparotomy (open surgery via midline incision). The surgeon will make an up and down incision (cut) on your abdomen (tummy) starting at the top of the pubic hair line and going up to, and sometimes beyond the belly button (umbilicus). Both keyhole and open surgeries are done under general anaesthetic (you are asleep).

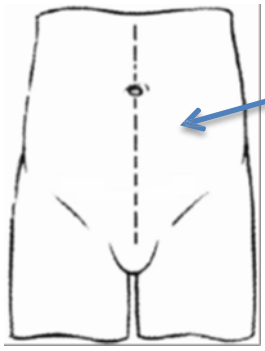


Diagram showing the location of the laparotomy incision

Depending on the type of womb cancer or if the cancer is found outside of the womb, you may be offered further treatment such as radiotherapy and/or chemotherapy. This will be discussed in our multi-disciplinary team meeting when all of your results are available.

## Can there be any complications or risks associated with these surgeries?

Before you have your surgery you will be told about the risks and will be asked to sign a consent form which will list the potential complications. Please ask questions at any time.

More 'serious' complications are listed below:

- General anaesthetic carries a small chance of complication. This will be discussed with your anaesthetic doctor before your surgery. It is important to realise that these risks and complications are rare and every care is taken to keep the risks as low as possible.
- Infection- The risk of post-operative infections is reduced by giving antibiotics around the time of surgery but infection can still sometimes occur in the chest, wound, pelvis or urine. Infections are usually easily treated with antibiotics. Infection happens to two women in every 1000.
- Bleeding (haemorrhage) - This may occur during the surgery or rarely afterwards. You may need to return to theatre in the rare case of internal bleeding after the surgery. Haemorrhage requiring blood transfusion happens to 23 women in every 1000.
- Injury to the ureters or bladder - the ureters carry the urine from the kidneys to the bladder. The ureters can be damaged at the time of the surgery. If noted, this damage will be repaired during the surgery. Some people may have some difficulty passing urine after surgery, this may mean needing a catheter in your bladder for a period of time. This is usually only for a few days but sometimes longer. Occasionally, injury is not noted at the time of surgery, particularly if a fistula develops (a connection between the ureter( tubes that drain the bladder) and a nearby organ). If this occurs you will be referred to a urologist (a doctor who specialises in urinary problems) This problems occurs in 7 woman in every 1000.
- Damage to the bowel can occur at the time of surgery and will usually be repaired during the operation. The risk of this happening is four women in every 10 000
- Clots (thrombosis) - It is possible for clots of bloods to form in the deep veins of the legs and pelvis. This is called a deep vein thrombosis (DVT). This will normally cause pain and swelling in the affected leg and is relatively simple to treat using blood thinning drugs (low molecular weight heparin). In rare cases it is possible for a clot to break away be deposited in the heart and lungs. If this occurs, it is a potentially serious complication but several measures will be taken to reduce the risk of this happening. Moving around as soon as possible after your surgery can help as can wearing special surgical stockings and having injections to thin your blood. 4 women in every 10000 develop blood clots to the legs or lungs after this type of operation.
- Lymphoedema/lymphocyst formation – If you require surgery to remove some of your lymph nodes from the pelvis or near your major blood vessels (aorta), you may develop re-accumulation of lymph fluid in your abdomen (tummy) or even in your legs (lymphoedema). This fluid accumulation may resolve over time, but occasionally you may be referred to a specialist Lymphoedema clinic. You can help the lymph fluid circulate and resolve by keeping active after surgery. The risk of developing lymphoedema after removal of pelvic lymph nodes varies from about 2 in every 100 women to 11 in every 100 women according to retrospective studies. The incidence likely varies depending on how much lymphatic tissue was removed.
- With every surgery there is a very small risk of death. The risk of death within 6 weeks of this type of surgery is 32 women in every 100 000 (rare).
-

Risks adopted from Royal college of obstetrican and gynaecologist (RCOG) guidelines on abdominal hysterectomy for benign conditions. Women who are obese, who have significant pathology (such as cancer), who have had previous surgery or who have pre-existing medical conditions must understand that the quoted risks for serious or frequent complications will be increased.

## Risks of laparoscopic surgery

Laparoscopic surgery (keyhole) usually means a shorter hospital stay and quicker recovery time. There is reduced scarring as there are smaller incisions (cuts) and smaller instruments are used during the surgery. Blood loss during this surgery is often less compared to laparotomy (open).

Due to your shorter hospital stay after laparoscopic surgery, it is very important that you inform us if you develop any problems once you are discharged home. These can be signs of infection or sepsis, and include:

- Tummy swelling
- Pain
- Fevers
- Shivers
- Passing urine from your vagina
- Bleeding from your vagina

Should any of these symptoms develop in the weeks following surgery please contact your Clinical Nurse Specialist or call Ward 21 at QEH on 0191 4452021 for advice.

More common risks that can occur from this surgery:

- Anaemia
- Fatigue / tiredness
- Pain/discomfort
- Bruising
- Urinary frequency or loss of control

## Risks of laparotomy surgery

With an open surgery your hospital stay will be longer. Recovery can take 6 weeks and sometimes longer. There is a risk of delayed wound healing.

More common risks that can occur from this surgery

- Anaemia
- Fatigue / tiredness
- Urinary frequency or loss of control
- Numbness, tingling or burning sensation around the scar which may take weeks or months to resolve
- Pain/discomfort
- Bruising
- Delayed wound healing
- Scarring of the skin or scar tissue inside (adhesions)

## How can I prepare for my surgery?

You should have been given the 'Enhanced recovery' booklet at the same time at this information leaflet. This will describe in more depth the ways in which you can help yourself to be as well as you can be for your surgery. It also considers exercises that you can perform to reduce your risks of complications and advice for what to expect when you leave the hospital and are recovering at home.

The following issues are important:

- Stopping or cutting down on smoking
- Eating a healthy diet. If your diet is restricted in any way please ask your team about a dietician referral. If you are overweight, please try and lose some weight.
- Where possible take some gentle exercise.
- Try to prepare for your discharge home, for example by stocking your freezer with easy to prepare food, arranging with relatives and friends to help with housework or childcare.

## How will I get the results of my surgery?

After your surgery your doctor will see you in the evening or the following morning. They will discuss the findings during the surgery with you as well as finding out how you are. The results of any tissues removed should be available seven to ten days after your surgery and we will discuss with you how you wish to receive the results

## Will I need further treatment?

This depends on the findings at surgery. This will be discussed with you at your follow up appointment if necessary.

## How long will it take to recover physically from my surgery?

It can take 6 weeks and sometimes longer to recover fully from your surgery. Details of what activities you can do when after your surgery can be found in the enhanced recovery booklet that you will have received in clinic. The ward staff will also provide information on your recovery before your discharge home.

## How will I feel emotionally after the surgery?

Surgery can be a very stressful event and many women feel tearful and emotional at first. Being tired and in pain can make these feelings worse. Some women find that once they are at home and have more time to think things through that they can feel very low in mood.

It may help for you to speak about your feelings at this time with your gynaecological oncology Clinical Nurse Specialist (contact details at the end of this leaflet.) They are able to offer increased levels of support, advice and guidance about your illness and can point you in the direction of other forms of support as you need it. Your nurse specialist can also help with intimate issues or concerns about your sexuality, body image, fertility menopausal issues or your sexual relationships.

## Possible longer term implications of treatment

Following your surgery you may experience some of these problems. Your medical and nursing teams are available to support you and to help to address any problems that may occur.

- Lymphoedema (swelling) - In some cases when the lymph nodes are removed a result can be lymphoedema. This is a build up of lymph fluid which mostly affects the legs. But it can develop in other body areas such as the abdomen (tummy area), genitals and pelvic area. If this were to occur you would be referred to a specialist Lymphoedema clinic.

- Menopause (if not already menopausal) – some of the main physical effects are vaginal dryness, hot flushes, mood changes and low libido (sex drive). This occurs when your ovaries are removed so your hormone levels reduce quickly. How long these symptoms last for is different for everyone. In some cases women can start HRT, however this will depend on the outcome of your surgery.

- Effects on sexual functioning (discomfort, bleeding, reduced libido)

- Emotional/social consequences of diagnosis and treatment

- Change in bladder/bowel habit

## Prescription exemption

As you have been diagnosed with cancer you are exempt from prescription charges. Contact your GP and they will issue a certificate for this.

# What support is available for me?

Clinical Nurse Specialist:

You should have contact details of a clinical nurse specialist (key worker) from your local hospital. Even though you are having treatment at Queen Elizabeth Hospital your local nurse remains an important point of contact for you. Contact details will be provided to you for the clinical nurse specialists from Queen Elizabeth hospital also. You are entitled to attend a holistic need assessment (HNA). This assessment can take place at your local hospital or Queen Elizabeth Hospital, at diagnosis, during any treatment you receive or once treatment has been completed. It gives you the opportunity to discuss concerns and fears they could be:

- Emotional
- Physical
- Spiritual
- Financial
- Practical

It allows both yourself and your clinical nurse specialist to put a plan in place. If you would like to arrange this please do not hesitate to contact your clinical nurse specialist.

# What happens when my treatment is complete?

In many cases, following surgery for endometrial cancer, no further treatment is required. You will be seen in clinic at QEH on a Tuesday afternoon for the results of your hysterectomy. You will see a Nurse Specialist at 6 weeks for your Holistic Needs Assessment and they will follow you up in a Nurse Led clinic. If you develop any symptoms between clinic appointments, then please contact them to arrange an urgent appointment.

If you are advised that you need radiotherapy or chemotherapy, an appointment will be made for you to see a Clinical Oncologist. Following your treatment you may be referred back to your Surgeon's team or the Nurse Led team for follow-up.

Follow up after treatment can vary depending upon the stage of your disease and the treatment you have had. Rather than having regular hospital appointments some women will have patient initiated follow up (PIFU). This is when rather than attend regular appointments you contact your clinical team if you have concerns. Some women will require regular appointments initially but as they recover they will also have patient initiated follow-up. Your clinical team will discuss this with you in more detail at the appropriate time and will provide written information for you.

# Research Projects

The NGOC department is actively involved in several research projects with the aim of increasing understanding of cancer and improving care of all patients. You may be approached by a member of the research team during your investigation, treatment or during follow-up to be part of a research project that you may be eligible to participate in. Whilst we encourage all patients to consider getting involved, this is not essential and your care will not be affected if you choose not to participate.

## How can I comment on the treatment that I have received?

Gateshead Health NHS Foundation Trust cares about the quality of care that you receive and strives to maintain high standards of health care. If you would like to talk to someone about any concerns, comments, compliments or complaints that you may have about your care we would encourage you to do so. You can do this by speaking to one of the healthcare professionals caring for you or by contacting the PALS (Patient Advice and Liaison Service) via the contact details at the end of this leaflet. When you are ready to be discharged from the ward, you will be provided a friends and family card. This can be filled in whilst on the ward or when you get home.

## Who can I contact for further information?

For queries about issues such as appointments, parking and transport please contact your consultant's secretary. Contact details can be found on the 'Information for patients' leaflet that you were given at your initial appointment or by contacting the hospital switchboard on 0191 4820000 and asking for the gynaecological oncology secretaries.

Clinical Nurse Specialists:

(Monday –Friday) - 8.30am -4.30pm (not including bank holidays)

Tel 0191 4453404 or 0191 482000 and ask for bleep 2361

Tel 0191 4452123 or 0191 4820000 and ask for bleep 2344

Tel 0191 4456707 or 0191 4820000 and ask for bleep 2341

Ward 21

24hrs Tel 0191 4452021

(Patient advice and liaison service) PALS

Tel 0800 953 0667

Email:
ghnt.pals.service@nhs.net

NHS
111

If you're worried about an urgent medical concern, you can call 111 to speak to a fully trained adviser.

Your GP telephone number :

## Useful reading

A practical guide to understanding cancer: Understand womb (endometrial) cancer.

This booklet is produced by Macmillan Cancer Support and is useful to read alongside this information leaflet. This can be accessed online or copy can be provided by your local support nurse.

## Other useful contacts

Macmillan Cancer Information & Support – Queen Elizabeth Hospital, Gateshead. Open Cancer information and support centre. Open Monday-Friday 10.00-16.00 Telephone answering service. Telephone on 0191 445 2979 email: Macmillaninfo@ghnt.nhs.uk

Macmillan Cancer Support:  0808 239 3783 7 – seven days a week, 8am - 8pm.

The following organisations provides advice and support for women diagnosed with endometrial cancer

The Eve Appeal - Telephone: 02076050100 or visit https://eveappeal.org.uk

Womb Cancer Support UK - Website: www.wombcancersupportuk.weebly.com- Email: wcsuk@hotmail.co.uk

Please use this page to note down any additional questions you may have

## References & Acknowledgements

http://www.cancerresearchuk.org/about-cancer/ovarian-cancer/treatment/surgery/types-surgery

http://www.christie.nhs.uk/media/2666/779.pdf

## Data Protection

Any personal information is kept confidential. There may be occasions where your information needs to be shared with other care professionals to ensure you receive the best care possible.

In order to assist us to improve the services available, your information may be used for clinical audit, research, teaching and anonymised for National NHS Reviews and Statistics.

Further information is available via Gateshead Health NHS Foundation Trust website or by contacting the Data Protection Officer by telephone on 0191 445 8418 or by email ghnt.ig.team@nhs.net.

**This leaflet can be made available in other languages and formats upon request**

NoIL677 Version: 3 First Published: October 2018 Last Reviewed: June 2021

Review Date: June 2023

Author: Laura Clifford & Miss Nithya Ratnavelu