

Saint Mary's Hospital
Manchester Centre for Genomic Medicine

Information for Patients

Risk-reducing surgery to prevent ovarian cancer (salpingo-oophorectomy)

Introduction

If you are thought to have a high chance of developing breast or ovarian cancer due to your family history, you may wish to consider surgery to remove your ovaries and Fallopian tubes. Being aware of the available facts will help you make an informed decision about whether this type of surgery is right for you.

Generally, this type of surgery is recommended only for women with a lifetime risk of ovarian cancer over 20%, after they have finished having children.

What is risk-reducing surgery (RRS)?

Risk-reducing surgery (RRS) for ovarian cancer is surgery that is effective in reducing the chance of developing ovarian cancer. It involves removing the ovaries and Fallopian tubes. The operation may be done using laparoscopic (keyhole) surgery.

Why have I been referred for risk-reducing surgery (RRS)?

Your specialist in the Department of Genetic Medicine has advised that you have a higher than normal chance of developing breast and/or ovarian cancer. He/she has advised that you may benefit from having your ovaries and Fallopian tubes removed and has referred you to a specialist surgeon (Gynaecological Oncologist) to discuss this further.

Agreeing to treatment

What are the benefits of this operation?

The aim of the operation is to reduce the risk of developing ovarian cancer in women who are at a higher risk of developing this cancer. It may also decrease the risk of breast cancer. The Clinical Genetics Team have identified that you are at increased risk of developing one or both of these cancers.

However, it is important to realise that risk-reducing surgery is not risk-eliminating surgery. There is still a small chance that you could develop ovarian or peritoneal cancer as microscopic cancer cells invisible to the naked eye may have started to grow in your abdomen or pelvis before your ovaries are removed. It is not possible to remove these cells during the operation. Primary peritoneal cancer can occur in high risk women, but is rarer than ovarian or tubal cancer.

What are the main advantages of undergoing surgery?

1. The overall risk of an ovarian type cancer is reduced by approximately 95%, leaving a residual 1-2% (1 in 50 to 1 in 100) risk of primary peritoneal cancer.
2. It decreases the risk of developing breast cancer by up to half in 'high risk' women if surgery is performed before the age of 45 years and may reduce the risk by more than this if surgery is performed before the age of 40.
3. It prevents benign disease of the ovaries (such as cysts).

What are the main disadvantages of undergoing surgery?

1. You will not be able to become pregnant once your ovaries have been removed.
2. The surgical removal of both ovaries will result in an abrupt onset of menopause if you have not already reached it. If this is the case, you may begin to experience menopausal symptoms, for example, hot flushes, night sweats, mood swings, tiredness, vaginal dryness and loss of libido (sex-drive). The symptoms of menopause can usually be overcome by hormone replacement therapy (HRT).
3. You will also stop having periods once your ovaries are removed. In addition, you may have an increased chance of developing osteoporosis (thinning of the bones) and heart disease if you have the operation done before you have reached a natural menopause. Again, these risks are minimised by using HRT. It is important to understand that if you have already had breast cancer, you will not be able to take HRT.
4. There is the small risk of complications associated with having surgery (details below).

Is there a chance that cancer can be found?

Occasionally, a very early microscopic ovarian or tubal cancer is found when the tubes and ovaries are examined following surgery. The chance of this occurring is approximately 1-3%. In this situation, you may need to undergo further surgery during the next few weeks. This usually involves a hysterectomy and biopsies, which is routine in the treatment of ovarian and tubal cancer.

Are there any alternatives to this operation?

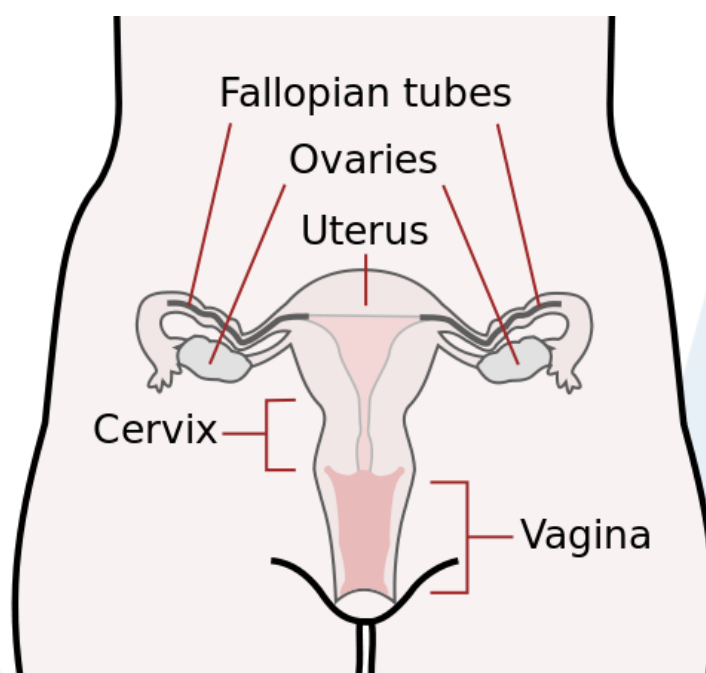
The operation is currently the best way of reducing the risk of developing ovarian cancer in women who are at high risk of developing this disease. For women who choose not to have the surgery, the options are limited. A trial assessing the effectiveness of ovarian screening is currently ongoing but is no longer recruiting patients. It may be possible to undergo regular CA125 blood tests, but these do not always detect cancer when it is easy to deal with.

An alternative is to consider using the combined oral contraceptive pill (OCP) which may give a 30-60% risk reduction for ovarian cancer. However, the use of the OCP may increase the risk of breast cancer and is not recommended after 35 years of age for prevention.

The operation

What is removed during my operation?

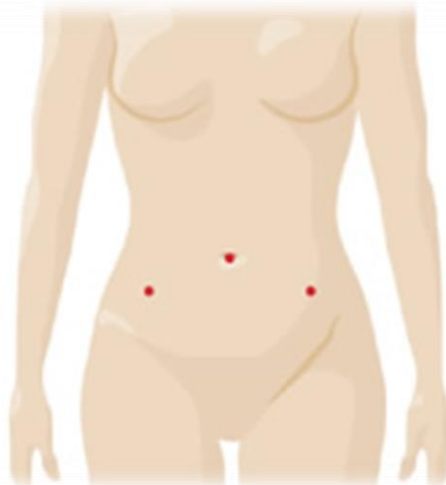
Both ovaries
Fallopian tubes



If you still have a uterus (womb) this is normally left in place. However there may be advantages to removing the uterus when considering HRT. This will be discussed with you at your clinic appointments with the geneticist and the gynaecologist.

Will I have a scar?

Yes. The surgeon will make three small incisions (cuts). The first is for the telescope (laparoscope) and is close to or in the navel (belly button or umbilicus). This is approximately 1cm long. Two further cuts will be made in the lower half of your abdomen (tummy), and these are approximately 5mm long. These are shown in the picture below. On occasion, a fourth small cut is made for a further instrument. Small dissolvable stitches are used to close the small skin wounds at the end of the operation and sometimes a special type of skin 'glue' may also be used. Normally these stitches dissolve on their own and do not need to be removed. If they are causing irritation then they can be removed after one week by the District Nurse. We will advise about this before you go home.



Are there any risks with this operation?

There are risks with having this surgery as there are with any operation, but it is important to realise that the majority of women do not have complications. Complications are more common in women who:

- Are overweight.
- Have had previous surgery through a midline (up and down/vertical) cut in their abdomen.
- Have had previous peritonitis or inflammatory bowel disease.
- Have significant problems with their general health, such as heart or lung complaints or diabetes.

If your surgeon thinks that you are at very high risk of a complication from laparoscopic (keyhole) surgery, then he/she may advise that you have the surgery done through an open operation (through a larger cut) instead.

The risks that can be associated with having a general anaesthetic and abdominal surgery include:

- Failure to complete the surgery using the keyhole procedure. This might result in you needing an 'open' procedure, in which a larger incision (cut) is made in the abdomen. The risk of this occurring is 1-3% (this includes equipment failure) in a woman with no other medical or surgical problems.
- Damage during the surgery to the bowel or to the urinary tract (including the bladder or ureters). The ureter is the tube that connects the kidney to the bladder on each side. The risk of damage to the bowel is approximately 0.6% and to the ureter is 0.3%. If damage to the bowel or urinary tract is suspected at surgery, an open operation through a larger incision (cut) may be carried out to explore and repair any damage.
- Haemorrhage (excessive bleeding) during or after the surgery. This is sometimes caused by damage to a large blood vessel. The risk of damage to a major blood vessel is approximately 0.1%. Haemorrhage may require a blood transfusion or a second open operation to stop the bleeding.
- Infection (including of the chest, wound, drip line, bladder, blood).
- Thrombosis (blood clot), including pulmonary embolus (a blood clot in the lung).
- Problems at the wound openings/scars (including hernia).

Consent to treatment

Your surgeon will discuss the treatment that has been recommended for you and will explain how it will affect you. Once you have had all of your questions answered to your satisfaction and any concerns have been addressed, we will ask you to sign a consent form. This is an official form that you sign giving your permission for the operation to proceed. You will be given a copy of this form to keep for your records.

Will I need any tests before my operation?

Yes. You will need to have some tests done to ensure that you are physically fit for a general anaesthetic and an operation. A separate appointment will normally be arranged for you 1-2 weeks before your surgery so that these tests can be done. This is called a 'pre-admission' or 'pre-operative' appointment. At the pre-admission appointment you will see a specially-trained nurse who will take details of any health problems and surgery that you have had.

The nurse will also make a list of any medication that you take. You will have your blood pressure checked and the nurse will listen to your chest for any heart or breathing problems. The nurse will also arrange any blood tests or other tests that you need. These may include a recording of your heart beat (ECG) and/or a chest X-ray. A blood sample will be taken to check that you are not anaemic and to identify your blood group in case you need a blood transfusion.

When will I come in for my operation?

You will be admitted to the ward on the day of surgery or occasionally the day before surgery. This will depend on what time your operation is scheduled for and whether there are any special considerations or other health problems.

What happens on the day of my operation?

You will not be allowed to have anything to eat or drink (including chewing gum or sweets) for a number of hours before your operation.

You will be advised about this at the pre-admission visit.

Before going to the operating theatre, you may be asked to take a bath or shower (depending on when you were admitted) and change into a theatre gown. All make-up, nail varnish, jewellery (except wedding ring), dentures and contact lenses must be removed. You will be provided with a pair of special compression stockings to wear. These help to reduce the risk of developing a blood clot (thrombosis).

What happens during the operation itself?

Before your procedure, you will be given a general anaesthetic. This means that you will be not be awake during your operation. When you are asleep the surgeon will perform your operation through three or four small incisions (cuts) as described earlier in this leaflet. The surgeon will put local anaesthetic in these cuts at the beginning of the operation to reduce any discomfort after surgery. A catheter (tube) is usually placed in your bladder during the operation to allow accurate measurement of the urine that you produce during and/or after the surgery and to help prevent injury to the bladder. This might be taken out immediately after the operation or left until later, for example, when you are less sleepy. Dissolving stitches and/or skin glue will be used to close the incisions (cuts).

What will happen after my operation itself?

When your operation is finished, you will wake up in the operating theatre or recovery room. You might have an oxygen mask on your face to help you breathe. You may feel sleepy.

After this procedure, most people will have a small, plastic tube in one of the veins of their arm. This might be attached to a bag of fluid (called a drip), which feeds your body with fluid until you are well enough to eat and drink by yourself. While you are in the recovery room, a nurse will check your pulse and blood pressure regularly. When you are well enough to be moved, you will be taken back to the ward.

Sometimes, people feel sick after an operation, especially after a general anaesthetic, and might vomit. If you feel sick, please tell a nurse and you will be offered medicine to make you more comfortable.

When can I eat and drink?

Usually following surgery you will be able to drink fluids when you are ready. If you feel hungry, you can usually have something light to eat soon after the operation.

How long will I be in bed for?

After this procedure, we will try to get you mobile (up and about) as soon as we can to help prevent complications from lying in bed.

When can I go home after my operation?

Most people who have this type of procedure will need to stay in hospital for 6-23 hours after surgery. Usually it will be possible for you to return home on the day of surgery but on occasions you may need to stay longer. This will depend on how quickly you recover from your surgery and whether there have been any problems or complications with the surgery or anaesthetic. Sometimes we can predict whether you will need to stay for longer than usual - your doctor will discuss this with you before you decide to have the procedure.

When can I resume normal activities including work?

You can usually resume normal activities including gentle work within 48 hours after your operation. Often you will want to wait a little longer before resuming more vigorous activity. You may drive 48 hours after the procedure if you feel comfortable. If you have to have your surgery through a larger 'open' incision, then it will take longer to resume normal activities and it will also take longer to be able to drive and perform an emergency stop comfortably.

We advise you to contact your car insurers for advice on driving following your surgery.

How long will it take to make a full recovery from my surgery?

Following uncomplicated keyhole surgery you should make a full recovery within 1-2 weeks. In the days after the procedure you should feel a little better with each passing day. If you do not seem to be making a steady recovery then this may indicate a complication and you should contact the ward that you were on for advice. You will be given contact details for this purpose.

Do I need to come back for a check-up?

After the operation, you will be given information about how you will receive results of your surgery. Usually a letter will be sent with the results as soon as these are available. The follow-up is tailored to your requirements and a clinic appointment will be sent if your doctor thinks this is necessary. If, however, you are having significant problems with your recovery then we would like to see you and we will arrange either a review on the ward or a clinic visit if you call us.

We will send your ovaries and Fallopian tubes to the laboratory for routine checking even if they look normal. It is not common to find any cancer in the ovaries or Fallopian tubes when we remove them in women with a family history. Occasionally, however, we do find signs of an early cancer. If this is the case with your samples, we will arrange to see you to discuss whether any further surgery or treatment is needed.

Are there any long-term side effects?

If you have not already experienced the menopause, you will have a premature menopause by having both of your ovaries removed. This means that your periods will stop permanently and you will be unable to achieve a pregnancy. You may also experience menopausal symptoms such as hot flushes or night sweats. Some women suffer from reduced vaginal lubrication and vaginal dryness/irritation in the months and years following removal of their ovaries. This can lead to discomfort during sexual intercourse. Some women have a lack of interest in sex (loss of libido). If you have already experienced the menopause, then by having your ovaries removed you are unlikely have any menopausal symptoms, although removal of the ovaries after the menopause can lead to reduction in libido in some women.

Will I need Hormonal Replacement Therapy (HRT)?

Hormone Replacement Therapy (HRT) will control most of the symptoms of menopause. Women below the age of 50 who have this surgery should consider taking HRT to avoid menopause symptoms and to minimise the chance of bone and heart disease.

Women with an inherited risk of ovarian cancer (high risk women) may also be at risk of breast cancer and therefore may be concerned about using HRT. If you are concerned, it is important to be aware that the situation is very different for women who have reached the menopause compared with women who have not reached the menopause. It is also important to understand that if you have already had breast cancer, you may not be able to take HRT.

- **Women who have not reached the menopause**

If HRT is taken after removal of the ovaries, it is replacing hormones that would have been naturally produced by the ovaries until the menopause (average age 51 years). There is no evidence that use of HRT in this situation increases the risk of breast cancer. Indeed, the balance of evidence suggests that pre-menopausal removal of the ovaries followed by HRT reduces the risk of breast cancer, possibly because the dose of oestrogen in HRT is less than the levels that would have been produced naturally.

In women with a known BRCA1 or BRCA2 mutation, then removing the ovaries and Fallopian tubes before the age of 40- 45 decreases the risk of breast cancer by about 50% irrespective of HRT use. HRT has important benefits in the short term, reducing the risk of bone loss and therefore osteoporosis, and potentially protective cardiovascular effects. HRT has been shown to improve quality of life.

- **Women who have reached the menopause**

A woman is considered to have reached the menopause if she has not had a period for at least 12 months. Studies have shown that HRT use for over five years increases the risk of breast cancer in post-menopausal women. Routine HRT use after the menopause is not recommended particularly in women at increased risk of breast cancer. However, occasionally the symptoms of the menopause may be so marked that the benefits of HRT outweigh this concern. In these circumstances use of HRT may be advised after careful consideration and discussion with your doctor.

Difference between types of HRT

Women who do not have a uterus can take oestrogen-only HRT, which has fewer side-effects and is not thought to increase breast cancer risk significantly. Women with an intact uterus need to take combined HRT which is safe for breast cancer risk in short-term use, especially before the natural menopause age.

Vaginal HRT

This is a type of HRT which usually contains oestrogen only and is most given as a tiny pessary (tablet) that you insert into the vagina with a very thin applicator, very similar to inserting a tampon. Alternatively, a cream can be used instead.

This type of HRT is useful in treating some of the vaginal and bladder symptoms that may develop some weeks or months after having the menopause such as dryness, irritation, discharge or needing to empty the bladder more frequently. The HRT works directly on the skin of the vagina to keep it supple and healthy and can also prevent some of the effects that the menopause has on the bladder. Only a very tiny amount of the hormone is absorbed into the blood stream and this type of HRT can be used in women who still have a uterus (womb). It is also safe for treating symptoms of vaginal irritation and soreness in women that have had breast cancer but we would recommend that you discuss this with either your gynaecologist or breast specialist first.

If you are under 50 years of age and decide not to have HRT we would recommend that you have a bone density (DXA) scan to assess your bone strength and this may need to be repeated.

Will I still need cervical smears?

If you still have your uterus (womb), then you should continue to go for your cervical smear when invited. If you have had a hysterectomy with removal of your uterus (womb) and cervix (neck of the womb) then you do not normally need to have any further cervical smears. Your gynaecologist will advise you about this.

Will I need long-term follow-up?

If you are known to be a carrier of a BRCA1 or BRCA2 gene fault, the regional genetics service will maintain contact via the genetic register system, although you should contact the department if you have any queries or would like a further appointment.

Will I be asked to be involved in research?

Research into new treatments and better ways of providing healthcare is another important component of our work.

You may be asked if you would agree to participate in a research project, however, you are under no obligation to take part and you have the right to decline or to withdraw from the research at any time, even if you do initially agree.

For more information

If you need more advice about any aspect of Angelman Syndrome, you are welcome to contact:

Manchester Centre for Genomic Medicine

Sixth Floor
Saint Mary's Hospital
Oxford Road Manchester M13 9WL

Telephone: (0161) 276 6506 (Reception)

Facsimile: (0161) 276 6145

Department staffed Monday - Friday, 9.00 am to 5.00 pm.

Website: www.mangen.co.uk

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio).

Seen in clinic by (doctor): _____

And (Genetic Counsellor): _____

Telephone number: _____

Family reference number: _____