

# Risk-reducing bilateral salpingo-oophorectomy

Clinical genetics information for patients



We have written this booklet for women who are considering having a risk-reducing bilateral salpingo-oophorectomy (RRBSO). You may be thinking about this if you have a strong family history of ovarian cancer or if you have been found to carry a genetic variant that increases your risk of ovarian cancer. It explains what an RRBSO is and what the operation involves.

The decision as to whether to have this operation is a difficult one to make. We hope this booklet will help to answer some of the questions you may have and help you decide whether this operation is right for you. If you have any further questions or concerns, please speak to a member of our team or your gynaecology team.

Please note that this type of surgery is usually only recommended for women:

- with a lifetime risk of ovarian cancer of 10% or more
- who have finished having children
- who are aged 35 years or older

### **What is an RRBSO?**

This is an operation where both your ovaries and fallopian tubes are removed to reduce your risk of developing ovarian (and fallopian tube) cancer. An oophorectomy is an operation to remove an ovary. A salpingo-oophorectomy is an operation to remove an ovary and fallopian tube. Bilateral means both ovaries (and tubes) and unilateral means one ovary (and tube).

Having an RRBSO will greatly reduce your risk of developing ovarian cancer but it will not remove your risk completely. Please be aware that despite having surgery, there is still a very small risk that you may develop a primary peritoneal cancer (a cancer that forms in cells in the abdomen) from cells that cannot be removed during surgery.

### **What are the ovaries?**

The female organs include the uterus (womb), ovaries, fallopian tubes, cervix, vagina and vulva. They are situated in the pelvis, close to the bladder and the rectum.

The ovaries contain eggs and form part of the reproductive system. During the reproductive years, the ovaries release an egg each month, which travels down the fallopian tube into the womb. If the egg is not fertilised by the male sperm, it is shed during a woman's period.

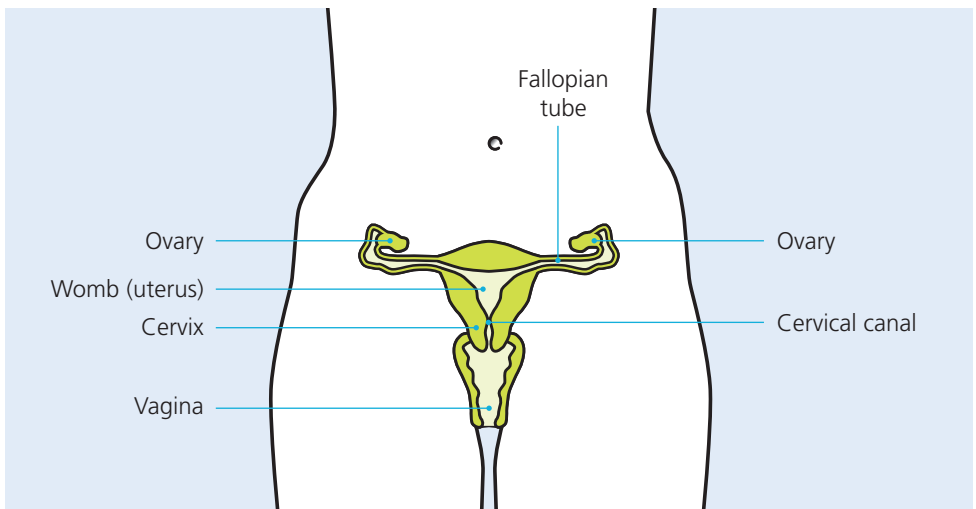
The ovaries produce sex hormones, including oestrogen, progesterone, and testosterone.

Production of these hormones decreases as a woman approaches menopause (when periods stop). For most women, this happens in their late 40s or early 50s. The average age of the menopause is 51 to 53 years.

## Family history

In the general population, ovarian cancer affects around one in every 70 women during their lifetime. For most women who are diagnosed with ovarian cancer, the cancer will not be caused by an inherited genetic variant.

You may be at an increased risk of ovarian cancer if you have two or more close relatives with ovarian cancer, or ovarian cancer linked with young onset breast or bowel cancer. In this situation, your medical team may refer you to a genetics service to discuss your family history with a doctor or counsellor who specialises in hereditary diseases.



Depending on your personal and family history, we may offer you a genetic test to help assess your risk. Variants in several different genes can increase a woman's risk of developing ovarian cancer. These include the BRCA1, BRCA2 and PALB2 genes, and less commonly, genes such as RAD51C, RAD51D and BRIP1.

## Ovarian cancer risk

Risk is the chance that something may or may not happen. Here, we are talking about the chance that you may or may not develop ovarian cancer. We all have different ideas of our own risk based on our feelings, beliefs, and experiences. Our genetics team can work out what risk there may be of a gene variant in your family by looking at your family history. We can also look at what your own risk of developing ovarian cancer may be.

## Screening for ovarian cancer

At present, we have no effective way of screening to pick up early-stage ovarian cancer in women who do not have symptoms. This means that we do not recommend any screening tests in women who are at higher risk.

You may have heard of a blood test looking at a marker in the blood called CA125. When a woman has ovarian cancer, CA125 can be raised, but it can also be raised in other conditions that are not cancerous. CA125 does not always go up in the early stages of ovarian cancer. In 80% of stage 1 ovarian cancers, CA125 is normal. Because of this, we do not recommend CA125 testing for women at increased risk of developing ovarian cancer.

## Research studies

There is evidence that ovarian cancer may start in the fallopian tube, rather than in the ovary. At present, we do not know if removing the fallopian tubes alone will protect women from ovarian cancer. However, there is some evidence that it may decrease the risk. This is currently being offered as part of a research study called PROTECTOR. You may wish to ask your clinical team if you are eligible to take part in this study or other research studies.

## Types of surgery

Most women will be offered an RRBSO to reduce their ovarian cancer risk. However, some women will be offered a hysterectomy (an operation to remove the womb). For some women, the surgeon may recommend that their womb, ovaries and fallopian tubes are removed. Each of these operations are carried out under general anaesthetic (a medicine that sends you to sleep).

Most women will be offered a laparoscopic (keyhole) RRBSO (a minimally invasive surgical procedure). For this surgery, the surgeon will make a few small incisions (cuts) in the abdomen (tummy) before inserting a laparoscope (a small tube that has a light source and a camera, which relays images of the inside of the abdomen to a computer display). The surgeon will then insert small surgical instruments into the abdomen to perform the operation.

If you need open surgery, the surgeon will usually make one large horizontal incision across the bikini line. A vertical incision (up to the tummy button) is less common.

Your surgeon will advise which type of surgery is most appropriate for you.

## Post-operative care

It is normal to experience some discomfort after having surgery. If you are in pain, let the team looking after you know and they can give you the right pain relief. Sometimes changing your position can help the pain. If you need help to do this, please ask the nurse.

After your operation, you should move about as soon as possible. This is an essential part of recovery because it helps prevent post-operative complications, such as deep vein thrombosis or a chest infection.

You may have an intravenous infusion (drip) in your arm to replace body fluids until you are able to drink and eat normally again.

You may need to have a small tube (catheter) put into your bladder to drain your urine into a collecting bag. This will be removed once you are able to pass urine without difficulty. You may also have a small drainage tube from your wound site (this is to stop excess fluid from collecting around the wound and will be removed about 48 hours after surgery).

## Recovery after surgery

After laparoscopic surgery, you will usually be able to go home the same day. It will then take about two weeks for you to recover.

After open surgery, you will be able to go home about three to five days after the procedure.

If you have a hysterectomy in addition to the RRBSO, your surgeon will advise you to have four to 12 weeks off work (depending on your job and social circumstances). You should avoid strenuous exercise and heavy lifting during the time you are off work. Depending on the type of surgery you have, you will not be able to drive for at least four to eight weeks. Your surgeon will discuss this with you.

## Sex life

Women often ask about their sex life after gynaecological surgery.

After laparoscopic surgery to remove both fallopian tubes and ovaries, you will need to avoid sexual activity for two to four weeks.

After a hysterectomy, you will need to avoid sexual activity for six to eight weeks. After this time, you can resume sexual activity as soon as you are comfortable to do so.

## Emotional changes

Some women experience emotional changes after having an RRBSO and/or a hysterectomy. This may be related to early surgical menopause and loss of fertility, as well as feelings linked to female identity.

If you are struggling with emotional changes after your surgery, please discuss this with your general practitioner (GP).

## Menopause

When a woman's ovaries are removed surgically before she has been through a natural menopause, she will go through the menopause immediately after the operation, regardless of her age. This is known as a surgical menopause.

The symptoms of surgical menopause vary from woman to woman. Some women may experience lots of symptoms which affect their daily life and others may not experience any symptoms.

The hormonal changes that occur as a result of surgical menopause can often feel overwhelming, especially for younger women. For this reason, it is important that you discuss the implications of this type of surgery with your gynaecologist.

## Hormone replacement therapy (HRT)

Hormone replacement therapy (HRT) is a treatment used to help relieve menopause symptoms, including:

- hot flushes
- night sweats
- vaginal dryness

It can also protect bone and heart health.

HRT replaces the hormones oestrogen and progesterone, which fall to low levels as you go through the menopause.

There are several ways HRT can be taken, including tablets, patches, and gels. If you are unable to take HRT, please discuss other options available to you with your GP.

Some women are concerned about breast cancer risk and HRT use. It is important to remember that HRT is only replacing the hormones your ovaries are not producing because you have had surgery. Increase in breast cancer risk has been linked to long-term use of HRT after the normal time of the menopause, not with replacing hormones after removal of the ovaries at an earlier age.

If you have any questions, please write these in the 'Notes' section (on page 11) as a reminder before you see the doctor or nurse.

## Glossary

### **Bilateral salpingo-oophorectomy**

Removal of both ovaries and fallopian tubes.

### **CA125**

A marker found in the blood which, if raised, may indicate an abnormality within the ovaries.

### **Consultant gynaecologist**

A doctor who specialises in women's reproductive diseases.

### **Genetic variant**

A permanent change in the DNA sequence that makes up a gene. This type of genetic change used to be known as a 'gene mutation'.

### **Gynaecology nurse specialist**

A nurse who specialises in women's reproductive diseases.

### **Hysterectomy**

Removal of the womb.

### **Laparoscopy**

A small operation where a micro-telescope is inserted into the tummy to remove the ovaries.

### **Laparotomy**

An operation where there is a surgical incision to remove the ovaries.

### **Menopause**

When the ovaries gradually stop producing hormones. This is the time when women stop having periods.

### **Prophylactic oophorectomy**

Removal of the ovaries while they are apparently healthy.

### **Ultrasound**

A scan using sound waves to look at inside the body.



## The team involved in your care are:

Consultant: .....

Tel no: .....

Genetic counsellor: .....

Tel no: .....

### Further information

If you need more advice about having a risk-reducing bilateral salpingo-oophorectomy or hysterectomy, please contact us:

- **Wessex Clinical Genetics Service**

Princess Anne Hospital  
Coxford Road  
Southampton  
SO16 5YA

Telephone: **023 8120 6170**

Website: **[www.uhs.nhs.uk/genetics](http://www.uhs.nhs.uk/genetics)**

## Useful contacts

- **Macmillan Cancer Support**

89 Albert Embankment  
London  
SE1 7UQ

Telephone: **0808 808 0000**

Website: **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

- **Ovacome**

52-54 Featherstone Street  
London  
EC1Y 8RT

Telephone: **0800 008 7054**

Website: **[www.ovacome.org.uk](http://www.ovacome.org.uk)**

- **Women's Health Concern (WHC)**

Spracklen House  
Dukes Place  
Marlow  
Buckinghamshire  
SL7 2QH

Email support service:

**[www.womens-health-concern.org/help/email.html](http://www.womens-health-concern.org/help/email.html)**

Website: **[www.womens-health-concern.org](http://www.womens-health-concern.org)**



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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**

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