

CONSIDERING SURGERY TO REDUCE YOUR RISK OF OVARIAN CANCER?

INFORMATION FOR WOMEN
AT HIGH INHERITED RISK



the women's
the royal women's hospital
victoria australia

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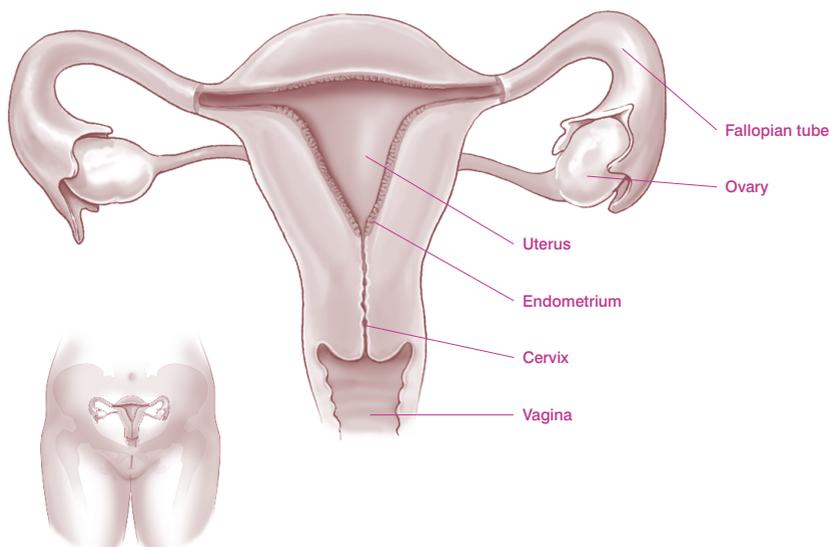
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ABOUT THIS INFORMATION

This information is for women at high risk of ovarian cancer. It describes the surgical procedure called Risk-Reducing Bilateral Salpingo-oophorectomy (RRBSO). It explains when the surgery is recommended, what it involves and how to manage the effects of surgery.

WHAT IS RISK-REDUCING BILATERAL SALPINGO-OOPHORECTOMY (RRBSO)?

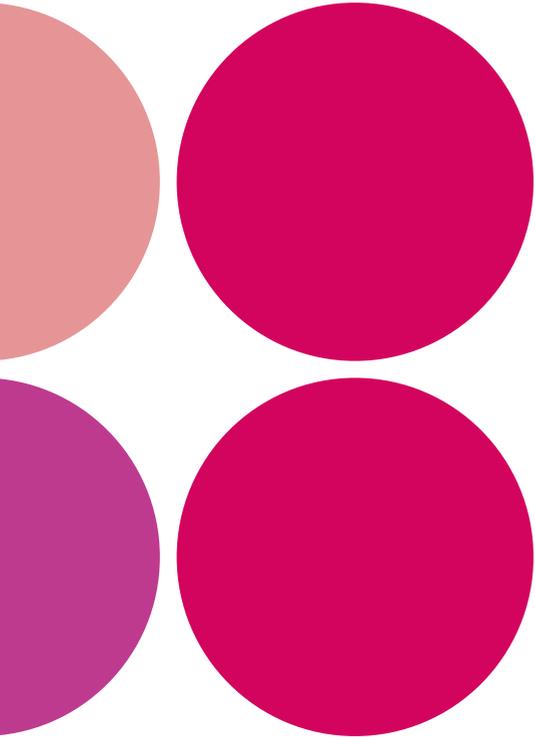
RRBSO is surgery to remove both ovaries and both fallopian tubes to reduce the risk of ovarian cancer. RRBSO does not usually include removing the uterus, cervix or vagina. Removing the uterus and cervix is called hysterectomy.



Female reproductive system

WHEN IS RRBSO RECOMMENDED?

RRBSO is recommended for women who are at high risk of ovarian cancer because of an abnormality in their genes that has been inherited. This is called a gene mutation. Most women at high risk of ovarian cancer carry the BRCA1 or BRCA2 gene mutation, but some other gene mutations (such as those causing Lynch syndrome) also increase the risk of ovarian cancer. These genes are inherited, meaning that they pass through families.



40 YEARS

MOST WOMEN WITH THE BRCA1 GENE MUTATION ARE ADVISED TO HAVE RRBSO BEFORE 40 YEARS OF AGE

45 YEARS

MOST WOMEN WITH THE BRCA2 GENE MUTATION ARE ADVISED TO HAVE RRBSO BEFORE 45

Some of these inherited genes also cause an increase in the risks of other cancers. For example, BRCA gene mutations increase the risk of breast cancer and Lynch syndrome increases the risk of uterine cancer and bowel cancer.

For women at high risk of ovarian cancer, RRBSO is the only intervention proven to reduce their ovarian cancer risk. RRBSO reduces ovarian cancer risk by 85–95 per cent.

Risk reduction is not 100 per cent because of the small risk of other cancers in the abdominal lining (the stomach area). This lining cannot be removed. For some women, RRBSO may also reduce their breast cancer risk. You can discuss whether RRBSO will reduce your breast cancer risk with your clinical geneticist or genetic counsellor.

Other procedures such as removing the fallopian tubes alone (without removing both ovaries), have not been shown to reduce ovarian cancer risk in high-risk women. Some studies of tissue removed from high-risk women with ovarian cancer suggest that the cancer may have started in the fallopian tubes. However, it is not known whether removing the fallopian tubes alone is effective in reducing cancer risk.

Unfortunately, there are no effective tests to detect ovarian cancer at an early stage or before it has spread. Blood tests and ultrasound (scans) are not effective for detecting early ovarian cancer in high-risk women.

The recommended age for RRBSO varies between women and depends on the gene mutation, personal and family history of cancer. Most women carrying the BRCA1 gene mutation are advised to have RRBSO before 40 years of age. Most with the BRCA2 gene mutation are advised to have RRBSO before 45.

If you have Lynch syndrome, you also have a higher risk of uterine (endometrial) cancer. Because of this, having your uterus removed (a hysterectomy) as well as RRBSO is recommended. Women who carry the BRCA gene mutation, and have completed their families, may also want to consider a hysterectomy at the same time as RRBSO. Including a hysterectomy means a bigger operation with a longer recovery time. For women carrying the BRCA gene, a hysterectomy has not been proven to reduce cancer risk.

**FOR WOMEN AT
HIGH RISK OF
OVARIAN CANCER,
RRBSO IS THE ONLY
INTERVENTION
PROVEN TO REDUCE
THEIR OVARIAN
CANCER RISK**

ABOUT THE SURGERY

A gynaecological oncologist or gynaecologist who has experience in performing RRBSO should perform the surgery.

- You will have a general anaesthetic, which means that you will be asleep during the operation.
- The operation usually takes between one to three hours.
- In most cases, keyhole surgery (laparoscopy) is used. This involves small cuts in the area around the stomach.
- You will usually be in hospital for the day only, but some women may need to stay overnight.
- If you have had several previous operations or infections in your abdomen, your doctor may recommend a different type of surgery called a laparotomy, which involves a larger cut in the abdomen (stomach area). Recovery from a laparotomy may take longer than from keyhole surgery and may need more time in hospital and off work.
- If you are working, you may need some time to recover, including time off work or away from usual duties. If the RRBSO is done by laparoscopy, this usually only requires one to two days off work. Recovery from a laparotomy may need four to six weeks off work. Your surgeon can give you specific advice about recovering from your surgery including when you can safely return to normal activities.
- Having a hysterectomy and RRBSO together requires a longer operation, needing more recovery time than RRBSO alone.

WHAT ARE THE EFFECTS OF RRBSO?

The effects of RRBSO are likely to vary depending on whether you have already gone through menopause.

For women who have not yet experienced menopause, removing both ovaries will cause immediate menopause. This is called surgical menopause. RRBSO also leads to permanent infertility.

You should discuss the effects of RRBSO with your clinical geneticist or genetic counsellor, the gynaecologist who will perform the surgery and/or your GP.

Infertility

Removing both ovaries leads to permanent infertility. This means you will not be able to get pregnant naturally after the surgery. If you have not completed your family and may want to have children in the future, there may be options to preserve your fertility for a future pregnancy. Options may include collecting and freezing eggs or embryos (fertilised eggs) before the surgery. This process is usually costly and does not always lead to a successful pregnancy. It may be possible to test embryos for gene mutations but this would usually mean an additional cost. These costs are not covered by Medicare and may not be covered by private health insurance. If you would like to have children in the future, discuss your options with a fertility specialist before RRBSO.

Surgical menopause

Most women experience natural menopause between the ages of 45–54. For women who have not yet gone through menopause, RRBSO will lead to immediate and permanent menopause. Surgical menopause can lead to symptoms such as hot flushes, night sweats and vaginal dryness. The effects of surgical menopause can vary. Some women have very mild symptoms or none at all and others have severe, longer lasting symptoms. Unfortunately, there is no way of predicting what your symptoms will be like after RRBSO or how long they will last.

45–54 YEARS

THE AGE MOST WOMEN EXPERIENCE NATURAL MENOPAUSE. FOR WOMEN WHO HAVE NOT YET GONE THROUGH MENOPAUSE, RRBSO WILL LEAD TO IMMEDIATE AND PERMANENT MENOPAUSE

MANAGING YOUR MENOPAUSE

Menopause is marked by changes in menstrual bleeding patterns and often by hot flushes, night sweats and vaginal dryness. Some women experience menopause at a younger age than most, especially those who have had chemotherapy for cancer treatment or high-risk women having RRBSO. Every woman's experience of menopause is different.

Most women experiencing normal menopause do not need medical treatment. We do not know whether women who have surgical menopause experience symptoms that are more severe or longer lasting than women who go through natural menopause or whether they are more likely to require treatment for their symptoms.

SYMPTOMS

WE DO NOT KNOW WHETHER WOMEN WHO HAVE SURGICAL MENOPAUSE EXPERIENCE SYMPTOMS THAT ARE MORE SEVERE OR LONGER LASTING THAN WOMEN WHO GO THROUGH NATURAL MENOPAUSE

Hot flushes

Hot flushes are one of the most common symptoms of menopause. They affect over 80 per cent (or, four in every five women) and typically start with a warm feeling in the chest or abdomen, which rises to the head and neck. Sometimes sweating also occurs. In natural menopause, hot flushes and night sweats are usually most severe in the year around the menopause and continue for around four years.

Vaginal dryness

Vaginal dryness affects around 60 per cent (or, three in every five women) after menopause. Symptoms can continue for many years and may include pain and discomfort during sex and discomfort or irritation of the vagina and vulva (outside the vagina). This is thought to occur when oestrogen levels drop after menopause.

Vaginal tablets or creams containing low-dose oestrogen can be used alone or with Menopausal Hormone Therapy (MHT) to reduce vaginal dryness. These are effective and usually safe to use after RRBSO. Your GP or menopause specialist can advise about treatments for vaginal dryness. If you have previously had breast cancer, talk with your oncologist before using vaginal oestrogens.

Sex and menopause

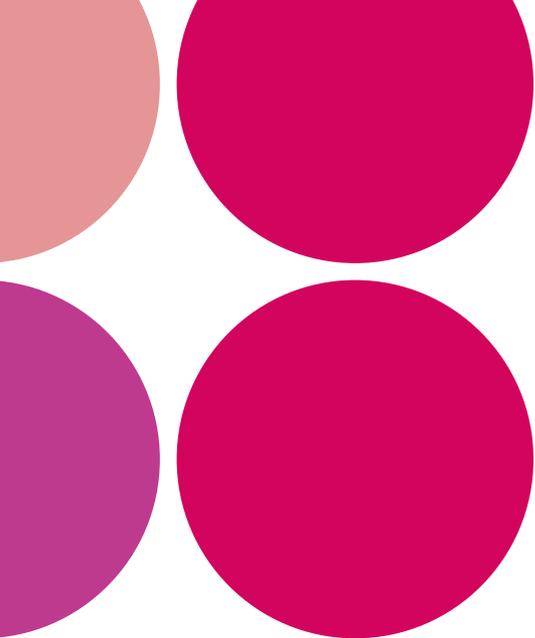
Some women notice a change in their interest and experience of sex after menopause. Some experience a loss of interest, desire or enjoyment in sex, which can be upsetting and may affect intimate relationships. Sexual function is complex and affected by your energy, self-image and relationships. Breast surgery for risk-reduction or for breast cancer treatment can also affect body image and sexual function.

Treatments for sexual dysfunction include vaginal oestrogens and lubricants for vaginal dryness, and counselling either alone or with your partner. Testosterone may also improve sexual function after menopause but it is not known whether testosterone products are safe to use in high-risk women.

Sleep disturbance

Disturbed sleep is more common with age. After RRBSO, some women notice a change in their sleep patterns. Night sweats, which disturb sleep, can be treated by hormonal or non-hormonal methods and other effective approaches include cognitive behaviour therapy (CBT). CBT teaches strategies that can help to change behaviours and assists a person to take practical steps to ease their symptoms. There are several CBT resources available online.

Disturbed sleep can affect your quality of life and lead to mood changes, such as depression. It can also be a symptom of depression. Talk with your doctor about treatment approaches to improve your sleep. For cancer patients, The Peter MacCallum Cancer Centre provides help with sleep through their Psychosocial Oncology Program called Can-Sleep.



Mood disturbances – anxiety and depression

Anxiety and depression are more common in women than men. Menopause may lead to an increase in depressive symptoms, which often improve after menopause. While not much is known about RRBSO and mood, studies have shown that this surgery may reduce cancer-related anxiety. Medication and therapies can assist:

- Some antidepressants can reduce hot flushes and help mood. A doctor can prescribe these.
- Try cognitive behavioural therapy (CBT) either with a therapist in a group or online.
- Join a support group and talk with others in a similar situation. Cancer Council Victoria can assist with suggesting the appropriate support group.

Heart disease

Heart disease is the leading cause of death in women. Early menopause may increase the risk of heart disease.

Proven ways of reducing risk of heart disease include:

- not smoking
- moderate use of (or no) alcohol
- having normal blood pressure, blood sugar and cholesterol levels
- exercising regularly
- maintaining a healthy weight
- eating a healthy diet
- effectively managing health problems such as high blood pressure, diabetes or high cholesterol.

These factors can also reduce the risk of diabetes and stroke.

Bone health

Early menopause can increase the risk of thin bones (osteoporosis) and fracture. A bone density scan can measure the thickness and strength of your bones and help to identify whether you are at increased risk of fracture. After early menopause women should have a bone density scan every two years until around age 50. Taking MHT can help to preserve bone and prevent fracture. If you cannot take MHT, your doctor may recommend other medications to prevent or treat osteoporosis. Lifestyle factors that help to keep your bones healthy include:

- weight bearing exercise
- adequate calcium and vitamin D
- not smoking.

Weight gain and muscle mass

Natural menopause leads to changes in body composition but does not usually cause weight gain. It is not known whether surgical menopause causes weight gain. Changes in body composition that women may notice include increased abdominal fat and loss of muscle mass. The best way to maintain a healthy weight and increase muscle mass is to exercise. Combined with a healthy diet, this will improve your general health and may reduce the risk of common long-term diseases such as diabetes and heart disease.

Incontinence

Urinary incontinence (leaking urine) is common in women of all ages but becomes more common with age. Risk factors for incontinence include pregnancy, childbirth and being overweight.

While menopause does not increase the risk of urinary incontinence, taking MHT as a patch or tablet may. Vaginal oestrogen however can improve symptoms of urgency (the sudden and compelling need to pass urine). The Continence Foundation of Australia has more information about incontinence.

EXERCISE

THE BEST WAY TO MAINTAIN A HEALTHY WEIGHT AND INCREASE MUSCLE MASS IS TO EXERCISE. COMBINED WITH A HEALTHY DIET, THIS WILL IMPROVE YOUR GENERAL HEALTH AND MAY REDUCE THE RISK OF COMMON LONG-TERM DISEASES SUCH AS DIABETES AND HEART DISEASE

MENOPAUSAL HORMONE THERAPY (MHT)

Women who experience menopause prematurely (under age 40) or early (under age 45) are usually advised to take menopausal hormone therapy (MHT) until around age 50. This treats symptoms of menopause and reduces the risk of osteoporosis and fracture.

MHT is generally safe for high-risk women, provided they have not had breast cancer. It is the most effective treatment for hot flushes and night sweats.

There are other medications that can treat hot flushes and night sweats which do not contain hormones, but these are not as effective as hormonal treatments and do not protect bones. They do not treat vaginal dryness.

HORMONE THERAPY

MHT IS GENERALLY SAFE FOR HIGH-RISK WOMEN, PROVIDED THEY HAVE NOT HAD BREAST CANCER. IT IS THE MOST EFFECTIVE TREATMENT FOR HOT FLUSHES AND NIGHT SWEATS

Drug-free options to treat hot flushes and night sweats include cognitive behaviour therapy (CBT), hypnosis and acupuncture. However, these treatments may not be as effective as MHT. A menopause specialist, gynaecologist or your GP can discuss these options with you.

The decision whether or not to take MHT depends on your wishes, your symptoms, your age and previous medical history.

Reasons to avoid MHT include previous breast cancer, blood clots in the legs or lungs, heart disease, untreated high blood pressure and some kinds of liver disease.

Women who still have their uterus should take combined MHT, which includes oestrogen and a progestogen (a hormone like progesterone). This progestogen is taken as a tablet or patch. It can also be given using an intra-uterine device (IUD) called Mirena, which may be inserted at the time of RRBSO. Discuss this with your surgeon before RRBSO.

Women who have had a hysterectomy or who have a Mirena only need to use oestrogen. This is given as a patch, gel or tablet. Your GP, gynaecologist or a menopause specialist can discuss the options with you.

BREAST SCREENING FOR WOMEN AT HIGH-RISK OF BREAST CANCER

BRCA mutations (BRCA1 and BRCA2) increase the risk of breast cancer and some other cancers.

Some women choose to take risk-reducing medication for breast cancer such as tamoxifen and some elect to have both breasts removed (a double mastectomy) to reduce their risk. Unlike ovarian cancer, screening for breast cancer can detect the disease earlier, which leads to improved cancer outcomes. The type of screening used for breast cancer in high-risk women depends on your age and whether you have reached menopause. It may include MRI, ultrasound and/or mammograms. Your family cancer clinic, breast surgeon, and GP can advise on the best screening program for you.

ONGOING CARE AFTER RRBSO

After surgery, your surgeon will refer you back to your GP who can:

- monitor your general health and bone health
- assess and manage the impact of your surgery, its side effects, and any ongoing issues
- provide information on cancer symptoms
- make sure you receive any necessary future screening specialist care if you are at high risk of any other cancers.

FOR MORE INFORMATION

Australasian Menopause Society

www.menopause.org.au

Includes a range of information about menopause, MHT/HRT and alternatives to assist women with their transition to menopause.

Betterhealth Channel

www.betterhealth.vic.gov.au

Provides easy to understand, high quality health information about a range of health issues.

Breastscreen Victoria

www.breastscreen.org.au

Breastscreen Victoria screens women for breast cancer. Their website includes information about the signs and symptoms of breast cancer.

Cancer Council Victoria

www.cancervic.org.au

This website includes information on a range of cancers and treatments, as well as where to access support groups.

Continence Foundation of Australia

www.continence.org.au

Provides information in English and a number of community languages about bladder and bowel health.

Counterpart

www.counterpart.org.au

Women who have a lived experience of cancer provide support to Victorian women who are experiencing breast or a gynaecological cancer.

Health Translations

www.healthtranslations.vic.gov.au

Translated information about health and wellbeing.

Jean Hailes

www.jeanhailes.org.au

Provides a range of information about women's health including menopause.

Osteoporosis Australia

www.osteoporosis.org.au

Information about bone health as well as preventing and living with osteoporosis.

Peter MacCallum Cancer Centre

www.petermac.org

Includes information about the physical, emotional and social impacts of a cancer diagnosis for people with cancer, their families and carers.

Royal Women's Hospital

www.thewomens.org.au

For information about a range of women's health issues including menopause, breast health and women's cancers.

VARTA

www.varta.org.au

VARTA provides independent information and support for individuals, couples and health professionals on fertility and issues related to assisted reproductive treatment. This includes IVF, surrogacy and donor-conception.

THANK YOU

We wish to thank those who generously contributed to the development of this booklet, in particular, those women who participated in our survey and provided feedback.

We would also like to thank the Western & Central Melbourne Integrated Cancer Service, who provided funding assistance for this project.

Feedback

The Royal Women's Hospital aims to develop health information that is useful for women and their families. We welcome your comments at all times. If you have anything you wish to tell us about this booklet please contact the Women's at rwh.publications@thewomens.org.au.

You can also send comments to:
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thewomens.org.au

