

RISK MANAGEMENT OPTIONS FOR WOMEN
AT INCREASED RISK OF DEVELOPING
OVARIAN CANCER

Information Booklet & Decision Aid



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WHO IS THIS BOOKLET FOR?

This booklet has been written for women who are at high or potentially high risk of developing ovarian cancer and would like to know more about reducing their risk of this disease and detecting it early.

Reasons you might be at increased risk of ovarian cancer could include:

- having a family history of cancer that suggests you are at potentially high risk of developing certain types of cancer including ovarian cancer.
- a genetic test result that indicates you are at high risk of developing ovarian cancer.

For either of these reasons, you may have already attended a family cancer clinic or other genetic counselling service, gynaecologist, surgeon and/or oncologist to discuss your breast and ovarian cancer risk in detail. These specialists can also discuss with you options to help you reduce your risk of ovarian cancer.

This booklet outlines some of the options available to you for reducing your risk of ovarian cancer. It presents the benefits and risks of each option to help you make an informed decision about the choice that is best for you.

Please contact your familial cancer clinic or specialist if you would like to discuss the information in this booklet or if you have any questions or concerns.

Please note Research studies that support statements made in the booklet have been referenced by a number. The complete list of references is at the back of the booklet.

The information in this booklet is correct at the time of publication. However, as research is ongoing, the information is updated every two years.

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HOW TO USE THIS BOOKLET

- Step 1** Read all the information contained in this booklet.
- Step 2** Consider the possible **advantages** and **disadvantages** of each management option.
- Step 3** Fill in the personal decision aid worksheet on pages **36 – 44** with a pencil to indicate your 'leaning' towards or away from each management option. In each box, fill in how important each advantage and disadvantage is to you.
- Step 4** Think about each option in turn and consider how much you 'lean' towards each.
- Step 5** Bring your leaning for each option forward to the 'balance sheet' on **46** to clarify your **overall** preference for a choice of risk management option.
- Step 6** Determine what your decision is.

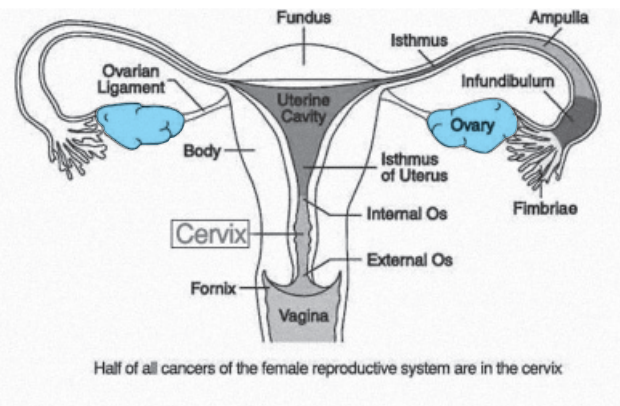
Please note An example is provided on **34** to illustrate how to fill in the decision aid. Although the circumstances outlined may be similar to your situation, the conclusion may not be the same one you would arrive at – everyone has their own values and emotions. Remember, there is no right or wrong answer, only what is right for you.

THE OVARIES & HOW THEY WORK

Most women have two small almond shaped ovaries. Each month, about two weeks after the start of a period, an egg is released from one of the ovaries. If the egg is fertilised, a pregnancy may occur. If a pregnancy doesn't occur, the lining of the uterus falls away and the woman has another period.

As well as storing and producing eggs, ovaries produce the female hormones **oestrogen** and **progesterone**. These cause a woman's breasts to develop, help make periods regular and work to build up the lining of the womb each month to support a potential pregnancy. The ovaries also produce a hormone called **testosterone**, which influences hair growth and sex drive.

As a woman gets closer to menopause, the ovaries make less of these hormones and her periods gradually become less frequent and finally stop. For most women, this usually happens between the early 40s and mid-50s.



OVARIAN CANCER

In Australia, one per cent of women (1 in 100) will develop ovarian cancer before the age of 75.^[1]

Ovarian cancer is a disease where malignant (cancerous) cells are found in the ovary. Ovarian cancer usually occurs in the outside lining of the ovary (called the *epithelium*). Its medical name, therefore, is *epithelial ovarian cancer*.

The disease is divided into four stages according to how far the cancer has spread. If the cancer is found while in the first stage when it is only in one or both ovaries, the survival rate is 90% or better.^[2]

Unfortunately, most women with ovarian cancer are diagnosed in the more advanced stages (3 and 4), when the survival rate is less than 20%. This is why women who develop ovarian cancer have one of the poorest survival rates amongst cancers.

This means early detection is very important, but it can be difficult. Early symptoms are often vague and can be similar to those of other common medical problems, which means that sometimes doctors don't immediately recognise it as ovarian cancer.

Early symptoms of ovarian cancer include:

- Pelvic or abdominal discomfort or pain
- Bloating/swelling in the abdomen or unexplained weight gain
- Vague but persistent gastrointestinal upsets such as gas, nausea or indigestion
- A change in bowel function and habits; constipation or diarrhoea

- Bladder or other unexplained urinary problems (such as frequent urination)
- Unusual vaginal bleeding
- Fatigue
- Weight loss and fever

Most women will experience these symptoms from time to time. However, only very rarely do these symptoms indicate ovarian cancer, so it's important not to panic. If you are experiencing any of these symptom(s) and they are unusual for you and **continue for more than a week**, see your doctor.

WHY DOES OVARIAN CANCER OCCUR?

Cancer occurs when cells in the body become abnormal and grow out of control.

Cell growth is controlled by genes. Genes are found in every cell in our body and contain the information that determines how our cells grow and work during our lifetime. This information is inherited from one generation to the next.

Sometimes, changes in the genes in ovarian cells build up and stop the genes from working properly and the genes become faulty. These changes that make the gene faulty are called mutations. As more of these important genes become faulty the cells grow faster and can lead to cancer. Mostly these faulty genes are not inherited and occur by chance. They occur more often in older women as part of the natural ageing process but the reasons for this are not yet fully understood.

WHAT ARE THE RISK FACTORS FOR OVARIAN CANCER?

There are many variables, called *risk factors*, which can influence a woman's chance of developing ovarian cancer.

The two most important risk factors are being a woman and getting older. A family history of breast and/or ovarian cancer is another important risk factor.

WHAT IS MEANT BY A FAMILY HISTORY OF BREAST AND/OR OVARIAN CANCER?

You have a family history if you have one or more blood relatives on the same side of the family who have or have had breast and/or ovarian cancer. These relatives could be on either your father's or mother's side of the family.

Some women with a family history of breast and/or ovarian cancer may have inherited a faulty gene that increases their risk of developing these types of cancer. The stronger your family history (the more people who've had breast or ovarian cancer on the same side of the family) the more likely you are to have a faulty gene causing a high risk for breast and ovarian cancer running in the family.

About 5% (1 in 20) of all breast and 10% (1 in 10) of all ovarian cancers can be explained by an inherited faulty gene. Clinicians don't fully understand what causes the other cases of these cancers.

HOW DOES YOUR FAMILY HISTORY AFFECT YOUR CHANCE OF DEVELOPING OVARIAN AND/OR BREAST CANCER?

You are at potentially high risk of developing breast and/or ovarian cancer if one or more of the following facts are true for you:

- 1 One close blood relative (mother, sister, daughter, aunt, niece, grandmother) has been diagnosed with ovarian cancer in a family of Ashkenazi Jewish ancestry.
- 2 A blood relative has been diagnosed with ovarian cancer at any age **and** a blood relative diagnosed with breast cancer before the age of 50, where these two women are close blood relatives (mother, sister, daughter, aunt, niece, grandmother) of each other.^[1]
- 3 Two or more blood relatives on the same side of the family have been diagnosed with breast or ovarian cancer – especially if that side of the family also has one or more of these factors:
 - additional relative(s) with breast and/or ovarian cancer
 - breast cancer diagnosed before the age of 40

- breast **and** ovarian cancer in the same woman
 - bilateral breast cancer
 - breast cancer in a male relative
- 4 A blood relative has had a genetic test that shows that they have an inherited faulty gene associated with ovarian cancer.
 - 5 Three or more close blood relatives on the same side of the family with cancers including early-onset bowel cancer (aged less than 50 at diagnosis), but also other types of cancers such as endometrial, ovarian, gastric, or cancers involving the renal tract. This may indicate a condition called Hereditary Non-Polyposis Colorectal Cancer (HNPCC) is running in the family.
 - 6 If you are suspected of having HNPCC.

The probability that there is a faulty gene causing a high risk of ovarian cancer in the family increases with the number of affected relatives, the number of affected generations, and a younger age of onset of disease.

If you need further clarification about your family history regarding your risk of developing breast and/or ovarian cancer, please contact your local family cancer clinic. Contact details are in the back of this booklet.

INHERITING A FAULTY GENE THAT MAKES YOU MORE LIKELY TO DEVELOP CANCER

You have a high risk of developing ovarian and other types of cancer if you have inherited certain faulty genes. However, this does not mean that you will definitely develop ovarian or another type of cancer.

Genes in which inherited faulty genes cause a high risk of ovarian and other cancers include:

- **BRCA1 and BRCA2:** If a woman has inherited a faulty BRCA1 or BRCA2 gene, she is at high risk of developing ovarian and breast cancer. It is difficult to say what the exact ovarian and breast cancer risk is for a woman who has a faulty BRCA1 or BRCA2 gene.

- **Mismatch repair genes:** There is a condition known as Hereditary Non-Polyposis Colorectal Cancer (HNPCC) which is caused by a faulty mismatch repair gene. Women who have inherited a faulty mismatch repair gene are at high risk of developing ovarian cancer as well as other types of cancers such as bowel and endometrial cancer (cancer of the uterus).

It is important to remember that if a woman has inherited one of these faulty genes, it does not mean that she is certain to develop cancer. While it is possible to estimate the risk of developing ovarian cancer, it is not possible to predict which women will actually develop ovarian cancer.

GENETIC TESTING

Depending on your family history, genetic testing may be possible. If your family is offered testing, the first step is almost always to do a genetic test of a blood relative who has already had breast and/or ovarian cancer, to try to find if a specific faulty gene runs in the family. If a faulty gene can be found, then other blood relatives can have a predictive genetic test to find out whether they carry the same specific faulty gene. However, some population groups (such as those with Jewish heritage) may be offered genetic testing without first having to test a family member who has already had breast and/or ovarian cancer.

If genetic testing is possible, the benefits and risks will be discussed with you in detail by your family cancer team. It is your choice whether or not you would like to go ahead with testing.

Knowing that you have a faulty gene that increases your risk of ovarian cancer can be very stressful, but many women find this information helpful in making important decisions about prevention strategies.

AT WHAT AGE DOES OVARIAN CANCER MOST COMMONLY OCCUR?

For the general population in Australia, The Cancer Council NSW reports that the average age at diagnosis of ovarian cancer is 63 years.^[3]

However, in women who have inherited a faulty breast and ovarian cancer gene, ovarian cancer may occur at a younger age; 51 years for women with a faulty BRCA1 gene and 62 years for women with a faulty BRCA2 gene.^[4, 5] In some families, ovarian cancer may occur as early as 35 years.^[6] However, this is extremely uncommon.

For women who have inherited a faulty HNPCC gene, the average age of diagnosis of ovarian cancer is reported to be around 45 years of age.^[7]

If a faulty gene has been identified in your family, you may want to discuss your approximate risk of developing ovarian cancer with your genetic counsellor or specialist.

Here are some questions you might want answered;

- Has a faulty gene been found in you or one of your blood relatives?
- If yes, which faulty gene?
- If ovarian cancer was to occur, what is the **average** age based on the specific faulty gene involved?
- What is the risk that you will develop ovarian cancer over the course of your life?

OPTIONS

FOR WOMEN AT RISK OF DEVELOPING OVARIAN CANCER

There are several options available to help women manage their risk of developing ovarian cancer, such as:

- **Bilateral Risk-Reducing Salpingo-Oophorectomy (RRSO)**
- **The oral contraceptive pill (The pill)**
- **Screening**
- **Watchful waiting**

Watchful waiting and screening do not reduce the risk of ovarian cancer but they may detect ovarian cancer if it develops. RRSO and the oral contraceptive pill do reduce the risk of ovarian cancer. All of these options are discussed in detail in this booklet.

When considering which option or combination of options would best suit you, it is important to take into account your own family history, age, stage of life and personal values. Also, as your situation changes, you may decide that a different risk management option is more suitable.

The following two charts outline some of the decisions that you may need to make, depending on whether you are **pre-menopausal** or **post-menopausal**. Each of the options to manage the risk of ovarian cancer is then discussed in more detail.

TYPES OF DECISIONS FOR PRE-MENOPAUSAL WOMEN

You may want children /more children

You don't want children/more children

Under 35

Over 35

Keep open option of having children

Would not consider RRSO at this time

Would consider RRSO

OPTIONS

Discuss

- 1 Consider RRSO at a later date?
- 2 The pill?
- 3 Screening?
- 4 Watchful waiting?

Discuss thoughts and feelings about RRSO with specialist doctors.

Find out what the surgery will mean for you

TYPES OF DECISIONS FOR WOMEN CURRENTLY EXPERIENCING MENOPAUSE AND THOSE WHO ARE POST-MENOPAUSAL

Would not consider RRSO at this time

Would consider RRSO

OPTIONS

Discuss

- 1 Consider RRSO at a later date?
- 2 Screening?
- 3 Watchful waiting?

Find out what the surgery will mean for you. Discuss your thoughts and feelings about RRSO with specialist doctors.

Please note: If you are post-menopausal, you may wish to skip the sections that follow called 'The oral contraceptive pill' and 'Surgical menopause', as they are not applicable to you.

OPTION 1A RRSO – A SURGICAL OPTION

Surgery to remove one or both ovaries is called an oophorectomy. A *preventive bilateral risk-reducing salpingo-oophorectomy* (RRSO) is surgery to remove both ovaries and both fallopian tubes before an ovarian cancer has occurred. 'Bilateral' means both and 'salpingo' means the fallopian tubes.

RRSO is the most effective means of reducing ovarian cancer risk in women who have inherited a faulty *BRCA1* or *BRCA2* gene, and it also almost halves the risk of breast cancer if performed before menopause.^[19, 20]

The Australian National Health and Medical Research Council (NHMRC) recommend the following for women at potentially high ovarian cancer risk:

Bilateral risk-reducing salpingo-oophorectomy (RRSO) is recommended in women with a faulty *BRCA1* or *BRCA2* gene, as it reduces the risk of epithelial ovarian cancer by at least 90%. It may also halve the risk of breast cancer. Ideally this option should always be discussed with women at potentially high risk of ovarian cancer.^[21]

At what age should I consider having RRSO ?

The age at which your risk of developing ovarian cancer becomes significantly increased varies depending on your family history and which faulty gene is present.

- The risk of ovarian cancer in women who have inherited a faulty *BRCA1* gene does not begin to rise significantly until about the age of 40 and for *BRCA2* until about the age of 50. Therefore, RRSO is generally performed in women who have inherited these faulty genes when they are in their late 30s or early 40s.^[22]
- However, as ovarian cancer has been reported in women in their 30s who have inherited a faulty *BRCA1* gene (although this is extremely uncommon), it is suggested that some women might consider having RRSO from the age of 30 to 35 years, or when they have decided

they don't want children or more children. If you have RRSO before you go through menopause, your risk of breast cancer may also be reduced by about 50%.^[19]

- Women with an HNPCC faulty gene are also recommended to consider preventive surgery in their late 30s or early 40s.^[7]

Before deciding whether to have this surgery, talk with professionals who have expertise in this area (such as a gynaecologic oncologist and/or familial cancer specialist). They can help you weigh up the advantages and disadvantages of the surgery, as well as the other options for managing your risk of ovarian cancer.

At what age has your doctor indicated that *your* risk of developing ovarian cancer will become significant? If you do not know, contact your familial cancer specialist or gynaecologist and ask them.

TYPES OF SURGERY

There are three main types of surgery for removing the ovaries: laparoscopy, laparotomy and hysterectomy. All three are carried out under general anaesthetic. In all cases, both ovaries are sent to a laboratory after surgery to check whether ovarian cancer was already present.

Laparoscopy

Most RRSOs are done using a *laparoscope* (a flexible tube which has a light and optical system for viewing inside the abdomen). This procedure may be unsuitable for some women (those who have had a number of previous operations, for example) and may not be available at all hospitals.

Using a laparoscope means that only very small cuts are needed in the navel and pelvic area. Once the incisions are made, carbon dioxide gas is used to make room for the laparoscope, which is inserted near the navel. Surgical instruments are then inserted through other small incisions, usually along the pubic hairline. This means the ovaries can be removed without major surgery. With laparoscopic oophorectomies, patients usually stay in hospital overnight, or sometimes for two or three days.

While laparoscopy causes fewer physical effects than major surgery, there will probably be some symptoms. Some women feel uncomfortable because the gas makes them bloated. Others may feel tired and have cramps and/or pain at the site of the incision for a day or two. However, most women who have laparoscopy report very few physical effects and find it takes about two weeks to return to a normal level of activity.

Laparotomy

This procedure involves removal of the ovaries through a slightly larger cut in the lower abdomen. A stay in hospital of five to seven days may be needed and recovery takes around two weeks. You can expect to return to your usual level of activity in approximately four to six weeks, depending on the type of family, social, work and other commitments you have.

Hysterectomy

Some women may consider having a hysterectomy, which means the removal of the womb, at the same time as the oophorectomy. A hysterectomy means that there is virtually no risk of developing cancer of the uterus (endometrial cancer) or cancer of the cervix.

Women who are taking Tamoxifen because of a previous history of breast cancer may wish to consider hysterectomy, as Tamoxifen is associated with an increased risk for endometrial cancer.^[23] Also, following hysterectomy, pre-menopausal women can take hormone replacement therapy (HRT), now sometimes called hormone therapy, with oestrogen alone instead of combined with progesterone (see section on HRT).

Women with a family history of HNPCC who have decided they don't want to have children or more children may also wish to discuss the option of hysterectomy when making their decision about preventative surgery, as they have an increased risk of endometrial cancer.^[24]

If you also have a hysterectomy, you'll probably have to stay in hospital for longer, and it may take you longer to recover than with the other surgical options.

Potential complications of surgery

All surgery carries a potential risk. The main possible complications are

infection, bleeding at the time of surgery requiring a blood transfusion, or the formation of blood clots. Fortunately these complications are uncommon.

Different surgical techniques are used depending on what your situation is (for example, if you have had previous surgery). If you decide to have RRSO, you will need to discuss with your doctor what type of surgery is most suitable for you and the risks associated with surgery. For example, women with HNPCC are usually advised to consider a hysterectomy as well as RRSO because of the increased risk of endometrial cancer as well as ovarian cancer.

Advantages of RRSO

- Studies show that RRSO can reduce the risk of developing ovarian cancer by over 90%.^[19, 25-27] Therefore, **this option reduces the risk of developing ovarian cancer more than any other risk management option.**
- RRSO also reduces the risk of developing breast cancer. Some studies have found that if RRSO is performed when a woman is still pre-menopausal, the risk of breast cancer in women who have inherited a faulty *BRCA1* gene may be reduced by almost 50%.^[20, 26, 28]

Disadvantages of RRSO

- RRSO lowers the risk of ovarian cancer a great deal but does not entirely eliminate it.^[29, 30] This is because some tissue similar to that found in the ovaries may be left behind, and cancerous cells may grow in this tissue.
- Once the ovaries are removed, a woman cannot have children.
- Pre-menopausal women having this procedure will experience the symptoms of a **surgical menopause**. A detailed discussion of this follows.
- While these procedures are covered by Medicare rebates, insured patients using private hospital facilities may have additional charges.

Tubal ligation

There is some data to suggest that tubal ligation (otherwise known as having your tubes tied) slightly reduces the risk of ovarian cancer in the general population.^[16] Some studies have also found a small risk reduction in ovarian cancer risk for women who have inherited a faulty *BRCA1* or *BRCA2* gene.^[11, 17, 18]

Tubal ligation may be an option for young women at high risk of ovarian cancer who have decided not to have children or more children and who may consider RRSO at a later date, but don't wish to undergo it at this stage.

SURGICAL MENOPAUSE

The most significant side effect of RRSO is what is called 'surgical menopause'.

For pre-menopausal women, RRSO causes symptoms like those which take place during menopause, which may be quite severe and can start within a few days after surgery. While these symptoms may not affect post-menopausal women so much, some women who are in the process of menopause when they have surgery may find their symptoms get worse after RRSO.

Natural menopause vs. surgical menopause

Menopause is the time in a woman's life when she stops having periods. This can happen any time between the late thirties and early fifties.

When menopause happens naturally, the hormones usually produced by the ovaries gradually run out, and this may result in a range of symptoms (see below). Periods may become irregular before they stop, giving women time to adjust to the changes happening in their body.

When menopause occurs because the ovaries are surgically removed, the drop in hormones is sudden. Periods stop immediately and some of the menopausal symptoms below are usually experienced.

What symptoms might occur?

Women going through menopause, whether natural or surgical, may

experience the following symptoms. Some women may have mild symptoms, while for others they may be more severe.

- Hot flushes and accompanying sweats, often at night
- Disturbed sleep
- Dryness of the vagina
- Less desire for sex
- Joint and muscle pain
- Uncharacteristic tiredness, anxiety or irritability
- Memory and concentration problems
- Depression

What other effects does menopause have on the body?

The ovaries produce a hormone called *oestrogen*, which helps to maintain bone strength and to protect against heart disease. After menopause (surgical or natural), less oestrogen is produced, which may affect the bones and the heart.

The bones

High oestrogen levels before menopause stop calcium being lost from the bones. A high level of calcium keeps bones strong and protects against a health problem called *osteoporosis*.

Osteoporosis means thinning of the bones – bones become weaker and break more easily. After menopause, osteoporosis is quite common because of a loss of calcium from the bones.^[31, 32]

The heart

Coronary heart disease is a common cause of illness and even death, and it affects women as they get older. It involves narrowing or blockage of the vessels supplying blood to the heart due to a build-up of cholesterol and other fats in the blood.

Oestrogen helps to control levels of cholesterol and other fats in the blood and helps improve blood flow to prevent the build-up of fats. After menopause, the drop in oestrogen levels may no longer prevent the build-up of fats in the blood vessels of the heart, meaning that some women can develop coronary heart disease.^[32]

Treating symptoms of menopause and reducing the risk of osteoporosis

Younger women who decide to have RRSO may be prescribed hormone replacement therapy (HRT) to prevent menopausal symptoms and/or to help reduce the risk of osteoporosis in the long term. Doctors once thought that HRT may have reduced the risk of coronary heart disease in post-menopausal women. However, extensive research has not proved any such protective effect and doctors now recommend against using HRT as a way of preventing coronary heart disease in post-menopausal women.^[33-35] There are also some disadvantages in taking HRT. These are discussed in the section below.

OPTION 1B HORMONE REPLACEMENT THERAPY (HRT)

Hormone replacement therapy is taken to replace the hormones, *oestrogen* and *progesterone*, which are no longer produced by the ovaries after menopause (natural or surgical).

HRT comes in various combinations and doses of oestrogen and progesterone (combination HRT) or oestrogen alone (for women who have had a hysterectomy). Natural alternatives to HRT may also provide relief from menopausal symptoms for some women.

How long a woman takes HRT depends on her individual needs and whether it is mainly for relief from menopausal symptoms or for bone health, or both.

You need to consider your personal opinion and attitudes towards taking HRT. Issues to consider include the inconvenience of taking medication and controversy about risks of HRT for high risk women.

HRT and breast cancer risk

Studies show that the oestrogen and progesterone in HRT may cause a small increase in the risk of breast cancer.^[12] **Post-menopausal** women taking combination HRT have been shown to have an increase in their risk of breast cancer.^[33, 35, 39] A recent review of the evidence for and against HRT use around the time of natural menopause found that combined HRT increases the risk of breast cancer, while oestrogen-only HRT does not appear to increase the risk.^[35]

The risk of breast cancer in **pre-menopausal** women at high risk for breast and ovarian cancer after RRSO who take HRT is unclear. There are two important points to consider. Firstly, the amount of oestrogen and progesterone in HRT is generally less than a pre-menopausal woman produces naturally. This means that specialists would not expect there to be an increased risk for breast cancer for younger women who have undergone RRSO and taken HRT. Secondly, studies suggest that RRSO decreases the risk of breast cancer in women at high risk for breast and ovarian cancer even when they take HRT.^[26, 37]

Each individual has different medical needs, so issues such as what is the most appropriate type of HRT and the optimal amount of time it should be taken will vary for each woman.^[38]

Please note: Pre-menopausal women with a prior diagnosis of breast cancer who are considering RRSO should discuss this issue with the doctor who is managing their previous breast cancer diagnosis.

Other concerns about HRT

HRT is not recommended for some women because of other health concerns. It is important to discuss HRT with your specialist before deciding to undergo RRSO. Take into account your own feelings and opinions before you make a decision about whether or not to take HRT.

Advantages of HRT...

- Relieves symptoms of natural or surgical menopause
- Reduces the risk of osteoporosis

Disadvantages of HRT...

- **Breast cancer risk**

The risk of breast cancer in **pre-menopausal** women at high risk for breast and ovarian cancer after RRSO who take HRT is unclear. However, RRSO itself reduces breast cancer risk if performed before a woman goes through menopause. Also, the amount of oestrogen in HRT is less than a woman produces naturally, so HRT is unlikely to increase risk of breast cancer.

There is some evidence to suggest that **post-menopausal** women on combination HRT have an increased risk of breast cancer. However, there seems to be little or no increase in risk for breast cancer for post-menopausal women on oestrogen-only HRT.^[35]

- **Endometrial cancer risk**

Taking oestrogen-only HRT increases the lifetime risk of endometrial cancer (cancer of the uterus). If progesterone is added to oestrogen (combination HRT) there is **no added** risk of cancer of the uterus.^[35, 40] However, combination HRT may slightly increase the risk of breast cancer.^[33, 35]

RRSO... WEIGHING EVERYTHING UP

When considering whether or not to have RRSO, it is also important to consider the effects of the surgery and the impact it might have on your body image and lifestyle. You should also discuss the possibility of taking HRT with your specialist before deciding to have RRSO.

For **pre-menopausal women**, the main considerations include:

- the loss of fertility
- effects of premature menopause (including the potential risk of accelerated osteoporosis and coronary heart disease)
- advantages and disadvantages of HRT after surgery

These considerations need to be balanced against your age and estimated lifetime risk of ovarian cancer. Remember that the incidence of ovarian cancer in women at high risk does not begin to rise significantly until about the age of 40. HRT can be tailored to individual women's needs and taken in the short term to see if it improves menopausal symptoms.

For **post-menopausal women** there are fewer considerations, but it is important that you discuss the procedure with your clinicians so you can make an informed decision.

Considering RRSO – the experience of women from an Australian clinic

A recent Australian study on women's attitudes to RRSO^[41] found that from 182 women attending a family cancer clinic for advice about their risk management options, 52 were at increased risk of developing ovarian cancer. Some of those 52 had already had RRSO (17%). Of the remaining women:

- 36% said that perhaps they would have surgery
- 28% said they would consider the surgery
- 28% were unsure
- 8% said they would not consider having RRSO

The experiences of women who have had RRSO

Some studies have assessed the psychological impact that RRSO has on women. One study found that RRSO reduced women's anxiety about developing ovarian cancer, and that 86% of women reported being satisfied with their decision to have the procedure.^[42]

An earlier study interviewed women who had had RRSO and found the following:^[43]

- **Pre-menopausal women:** Women reported that the effects of surgical menopause (hot flushes, loss of libido, mood swings) were relieved by HRT. However, one of the pre-menopausal women declined HRT and continued to experience the symptoms of surgical menopause, which impacted her quality of life. Most women in this study said they were very satisfied with their decision to have RRSO. However, the possible link between HRT and breast cancer risk caused some anxiety.
- **Post-menopausal women:** The post-menopausal women in the study had experienced very few negative effects from the procedure.

Some remarks that describe the experiences of the women in the study follow...

- **A pre-menopausal woman discussing her surgical menopause symptoms and her decision to take HRT:**
"I was just frustrated, tired, and upset...the fact that, God, do I have to go on like this for years? I was actually getting a bit depressed so... I made the most informed decision I could [to take HRT after surgery]...I don't know if I've made the right decision but I find I made a decision regarding my quality of life".

- **Comments from two pre-menopausal women discussing the impact of RRSO on their femininity;**
"I don't feel like I'm any less feminine, any less attractive, any less of a woman, any less anything".

"Although I had never wanted children, the choice had always been mine. Now I don't have that choice any more and it's made me kind of sad".
- **One woman describes the impact that the surgery had on her anxiety about developing ovarian cancer:**
"The advantage is...influencing destiny and possibly saving one's life and being proactive in preventing cancer".
- **Most of the post-menopausal women saw the decision to undergo the procedure as uneventful. Typical remarks were:**
"Why take the risk when it could take your life? When the cards are stacked against you, why wonder? It's just not worth it".

Some women decide that RRSO is not for them. One post-menopausal woman at increased risk of developing ovarian cancer declined RRSO for the following reason:

"Well you can't take everything out...where would you stop? I think that if I keep going for my check-ups, I'll be doing OK".

If you are considering RRSO, it is important to take as much time as you need to make the decision that is right for you.

OPTION 2 THE ORAL CONTRACEPTIVE PILL (THE PILL)

This option involves taking 'the pill', which protects against pregnancy by preventing ovulation.

Taking the pill has been shown to reduce the risk of developing ovarian cancer.^[10, 11] A 2007 study has found that use of the pill reduced the risk of ovarian cancer in women with a BRCA1 or a BRCA2 faulty gene. The maximum protection comes when the pill been taken for three to five years.^[11]

THE ORAL CONTRACEPTIVE PILL IS NOT A SUITABLE OPTION FOR POST-MENOPAUSAL WOMEN.

Advantages of taking the pill

- Least invasive method of potentially reducing the risk of ovarian cancer.
- If you stop taking the pill, you can have children/more children.
- Reduces the risk of ovarian cancer in women with an inherited a faulty *BRCA1* or *BRCA2* gene.

Disadvantages of taking the pill

- Not suitable for post-menopausal women.
- The pill may be associated with a slightly increased risk of breast cancer.^[12] A study on the increase in breast cancer risk for women with a strong family history of breast and/or ovarian cancer found that those who had used versions of the pill before 1976, with higher dosages of oestrogen and progestins, were at increased risk of developing breast cancer.^[13]
- Some research has also found a small increase in breast cancer risk in women who have inherited a faulty BRCA1 gene who have taken the pill. Those who took the pill before age 30, or had been on the pill for more than five years had a greater increase in breast cancer risk.^[14] However, a more recent study suggests that this increased risk is only associated with types of the pill with a high dose of hormones which were formulated before 1975.^[15] This study found no evidence of increased risk with current formulations of the pill for women with

a faulty BRCA 1 or 2 gene and actually found a significant breast cancer risk reduction for women who have inherited a faulty BRCA1 gene who had used lower-dose pills formulated after 1975.^[15]

- There are some women for whom the pill is not suitable. General health concerns relating to the pill should be discussed with your doctor.

OPTION 3 SCREENING TESTS FOR OVARIAN CANCER

Screening tests show whether a woman might have already developed ovarian cancer. The aim of screening, also known as surveillance, is to detect cancer as early as possible. There is no evidence that screening tests increase survival rates from ovarian cancer. However, they may be considered for high-risk women who have decided against RRSO.

If you choose not to have RRSO and decide to embark on a program of surveillance, the Australian National Health and Medical Research Council (NHMRC) recommend:

- Visiting the GP promptly with any health changes.
- Screening with transvaginal ultrasounds (TVU) **preferably using a system called colour flow Doppler imaging**. This can be started at any age, depending upon your family history and whether a faulty gene has been identified in you or another family member.
- Screening tests for other cancers such as a clinical breast examination or mammography. If you have a family history indicating HNPCC, the Guidelines recommend further examinations appropriate for such a family history.

In addition, a blood test which checks the level of a protein called CA-125 may also be appropriate for women who decide on a surveillance programme. Ultrasound, TVU, colour flow Doppler imaging and CA-125 blood tests are explained below.

A woman at increased risk of ovarian cancer should consider beginning these surveillance methods at the age recommended by her family cancer centre.

Transvaginal ultrasound

The aim of an ultrasound is to detect ovarian cancer at an early stage (stage 1), while it's potentially curable. There may not be any symptoms at this stage.

The type of ultrasound used for ovarian cancer screening is ultrasound via the vagina: *transvaginal ultrasound* (TVU). For more detailed information on this procedure, speak to your doctor or family cancer team. A pamphlet called 'About your ultrasound examination' may also be available from your local hospital.

TVU is the recommended and most common way of screening for ovarian cancer.

Sound waves are used to produce a picture of the ovaries and nearby organs. With TVU, an instrument that produces these sound waves is inserted into the vagina. This instrument is smaller and less intrusive than a vaginal speculum (which is used when taking a Pap smear). The ultrasound pictures show whether the ovaries are enlarged or abnormally shaped or positioned. An ultrasound does not cause any pain and usually takes about 15 minutes.

TVU should not be done during ovulation as this may lead to false positive results – this is a result that wrongly indicates an abnormality when there is no real problem.

Colour flow Doppler imaging

Usually TVU produces an image in black and white. When a system called *colour flow Doppler imaging* is used during a TVU, the image is in colour, making it possible to see if blood flow is normal in the blood vessels near the ovaries. This procedure takes about five minutes.

TVU plus the colour flow Doppler test represents the best-known method to detect ovarian cancer.^[8]

Blood test for CA-125

A blood test can be done to check for a protein found in the blood called CA-125. Raised levels of CA-125 may indicate ovarian cancer. This test can be used combined with ultrasound and may be more appropriate for post-menopausal women.

However, CA-125 testing has some limitations:

- The benefit of CA-125 screening in detecting ovarian cancer at an early stage is uncertain. There is a higher likelihood of false positive results in premenopausal women, which could lead to unnecessary further investigations and maybe even surgery. Research is currently looking at the rate of change of CA-125 over time rather than the level of CA-125 at one given time, and this may prove to give more accurate results.
- A raised blood level of CA-125 does not mean that a woman definitely has ovarian cancer. Other conditions such as fibroids, endometriosis, pelvic inflammatory disease and pregnancy can also increase CA-125 levels.
- Many women with early stage ovarian cancer do not have increased levels of CA-125. Research has shown that CA-125 is increased in only about 25-50% of women with stage 1 ovarian cancer. A woman may therefore be given a normal result even though an early stage cancer is present.

With all of the screening tests mentioned above, if there is an abnormal (positive) result, it does not mean ovarian cancer is definitely present but it does mean that further investigation is required.

Advantages of screening for ovarian cancer

- Relatively quick and painless.
- You can still have children, if you wish to.

Disadvantages of screening for ovarian cancer

- Unfortunately the screening tests currently available for picking up ovarian cancer are not consistently reliable or accurate. This means they cannot definitely determine if a woman has ovarian cancer.
- TVUs **cannot** distinguish between benign (non-cancerous) and malignant (cancerous) ovarian tumours. Therefore a false positive result can occur. This may lead to unnecessary surgery, which can be distressing.^[9]
- It is possible for a cancer to develop between tests. This is known as 'interval cancer'. However, this occurs in only a small percentage of women.

At present, there are no data that prove the effectiveness of screening in reducing deaths from ovarian cancer. Although women who have screening may have a better chance of being diagnosed at an earlier stage, this has not been proven.

OPTION 4 WATCHFUL WAITING

This option involves having your usual medical and physical check-ups and visiting your general practitioner promptly with any health changes.

Possible reasons for this approach:

- You are younger than the age that is recommended for screening or preventive surgery.
- You may want to have children/more children and would like to keep that option open.
- You believe that the other options are not appropriate for you at this time.

Advantages of watchful waiting

- You can have children.
- No side effects.

Disadvantages of watchful waiting

- It is not easy to recognise the signs and symptoms of ovarian cancer during the early stages, so it is likely to be missed.
- If ovarian cancer does occur and is only found at an advanced stage, it is unlikely to be curable.

PERSONAL Decision Aid^{WORKSHEETS}

How to use the personal decision aid worksheets

Step 1 Read all the information contained in this booklet

Step 2 Consider the possible advantages and disadvantages of each management option.

Step 3 Fill in the personal decision aid worksheets on the following pages with a pencil to indicate your 'leaning' towards or away from each management option.

In each box, fill in how important each advantage and disadvantage is to you. Fill in a large portion of the box if the factor is very important to you and only a small part if the factor is less important or relevant. If a factor isn't important or relevant to you, leave that section blank (see the illustrated example).

Step 4 Think about each option in turn and consider how much you 'lean' towards each.

Step 5 Bring your leaning for each option forward to the 'balance sheet' on to clarify your overall preference for a choice of risk management option.

Step 6 Determine what your decision is.

AN ILLUSTRATED EXAMPLE OF HOW TO USE THE DECISION AID

Sally's situation

Sally is in her early 30s and knew she had a high lifetime risk of developing ovarian cancer. Sally also plans to have another child in a couple of years' time, so she wanted to maintain her fertility.

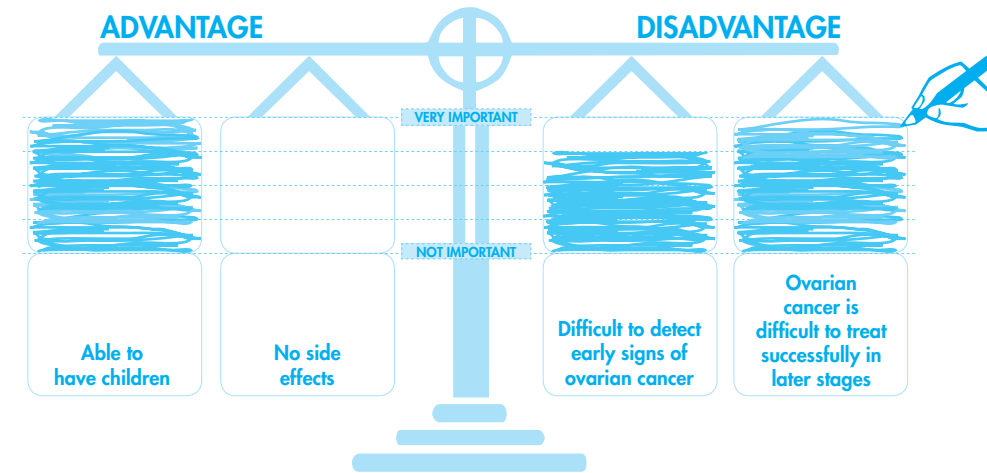
Step 1: Sally looked at all the options. **Step 2:** She thought about the possible advantages and disadvantages. Next, in **Step 3**, Sally filled in the weigh-scale pictures with a pencil to show her values. In each box, Sally filled in the amount that showed how important each advantage and disadvantage was to her. She filled in a large portion of the box if the factor was very important to her and only a small part if the factor was less important. Those factors that were not at all important or relevant to her, she left as is.

Here is an example of how Sally worked through her decision not to use watchful waiting to manage her ovarian cancer risk. On the advantage side, she thought maintaining her fertility was very important. On the disadvantage side, she thought that the difficulties in detection and treatment of ovarian cancer were also very important. On balance, Sally decided not to lean towards watchful waiting.

Step 2 Possible advantages and disadvantages of watchful waiting

Advantages	Disadvantages
Able to have children	The signs and symptoms of ovarian cancer are not easily recognisable during the early stages of the disease
No side effects	If ovarian cancer does occur and is only found at an advanced stage it is unlikely to be curable

Step 3 Sally's values: How important are these factors to Sally?



Step 4 Sally's leaning

Yes			Unsure			<input checked="" type="checkbox"/> No
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Watchful waiting

Watchful waiting

On balance, Sally decided **not** to lean towards **watchful waiting**

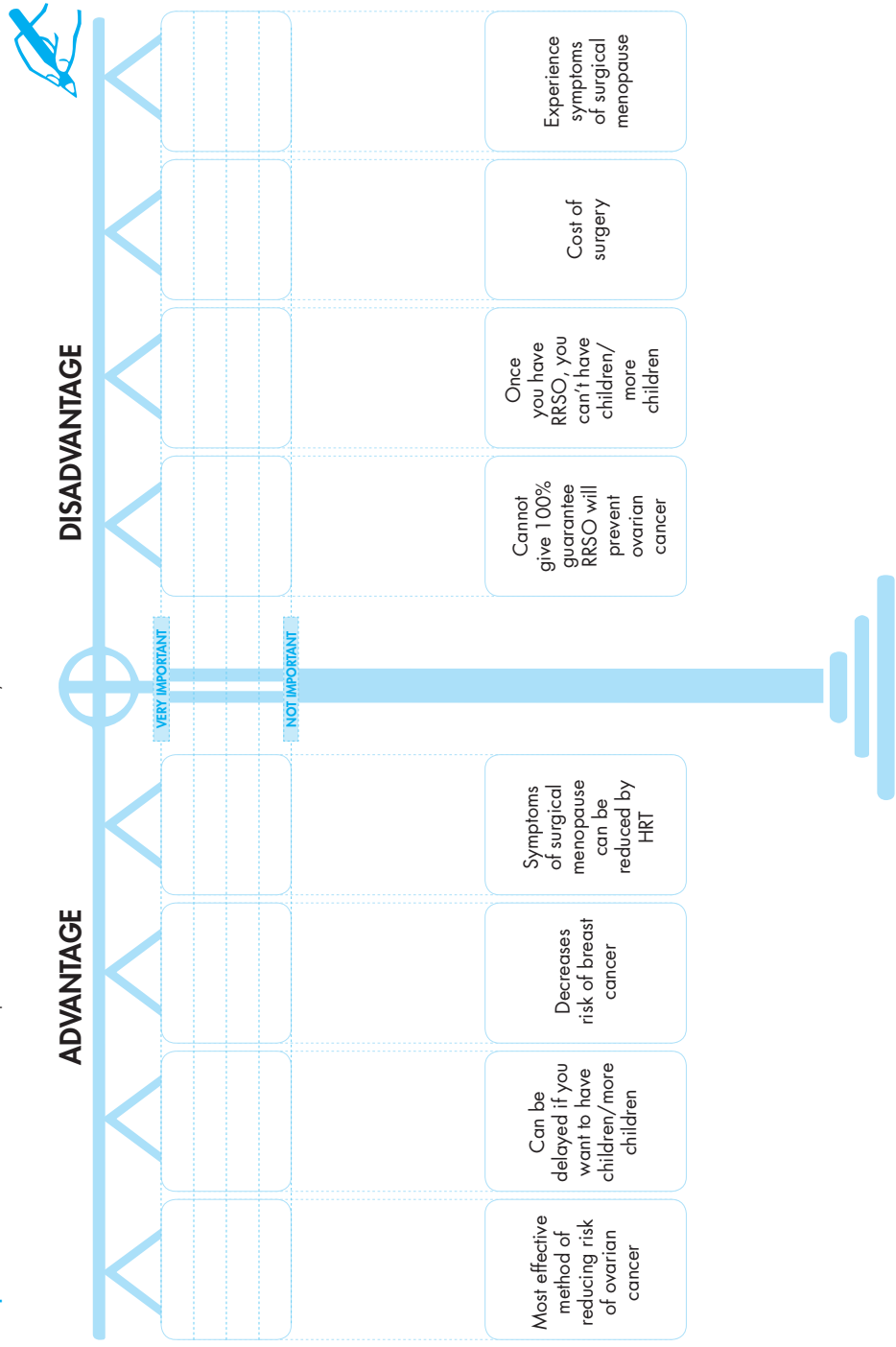
36 Personal Decision Aid Worksheet BILATERAL RISK-REDUCING SALPINGO-OOPHORECTOMY (RRSO)

Step 1 Briefly review the information in this booklet about managing ovarian cancer risk with RRSO and HRT.

Step 2 Possible advantages and disadvantages of RRSO

Advantages		Disadvantages	
Most effective method of reducing ovarian cancer risk	Can be delayed if you wish to have children/more children	Decreases risk of breast cancer	Symptoms of surgical menopause can be reduced using HRT
Not possible to give a 100% guarantee that ovarian/peritoneal cancer will be prevented	Once a woman has RRSO, she can't have children/more children – this may produce feelings of guilt or grief	Cost of surgery (While these procedures are covered by Medicare rebates, insured patients using private hospital facilities may have additional charges).	Pre-menopausal women having RRSO will experience symptoms of surgical menopause

Step 3 Your values: How important are these factors to you?



Step 4 Your leaning

Yes Unsure No

RRSO

RRSO

On balance, you decided

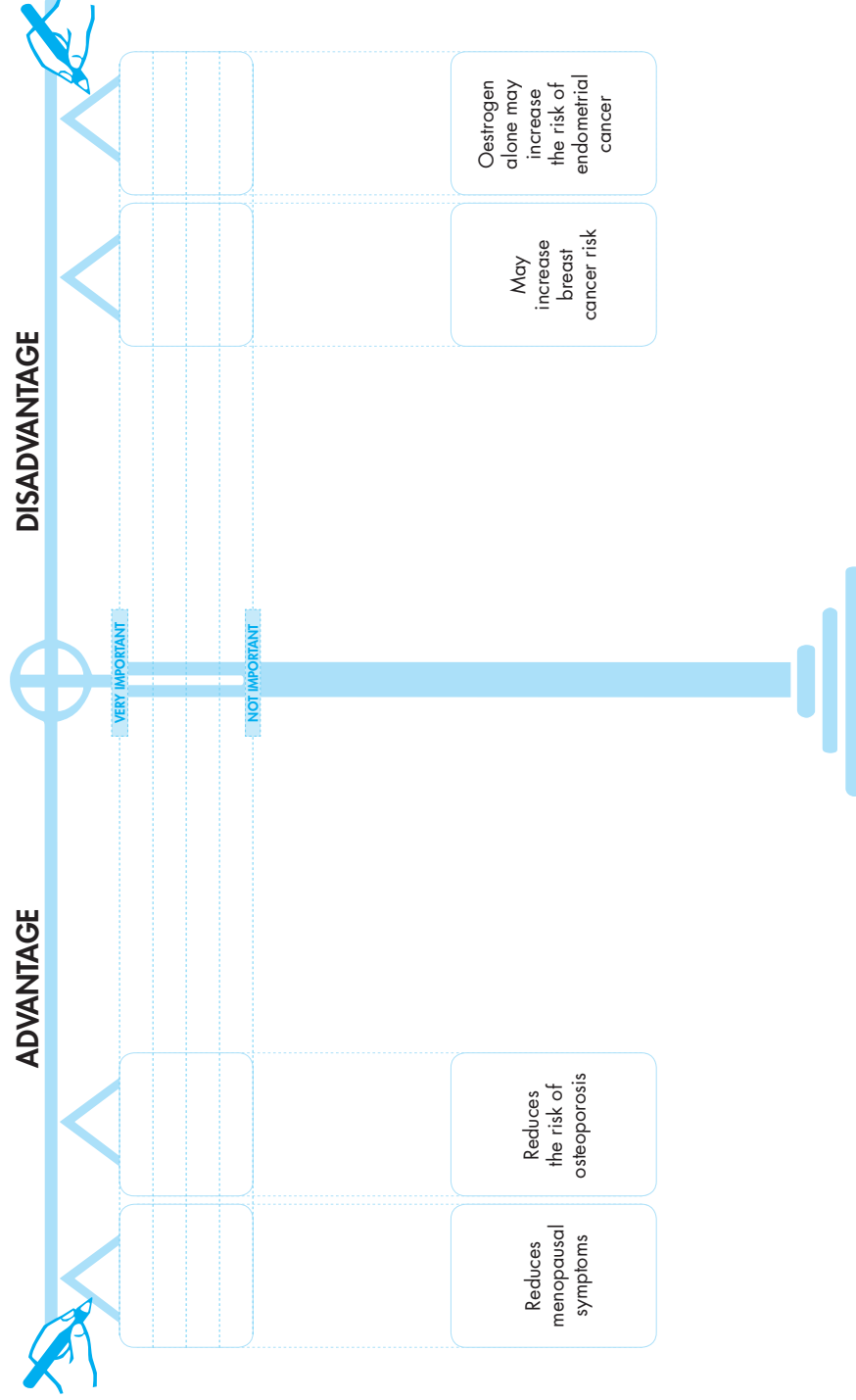
Personal Decision Aid Worksheet
HORMONE REPLACEMENT THERAPY (HRT)
 (for pre-menopausal women considering RRSO)

Step 1 Briefly review the information in this booklet about managing ovarian cancer risk with RRSO and HRT.

Step 2 Possible advantages and disadvantages of HRT

Advantages	Disadvantages
Reduces menopausal symptoms	May increase risk of breast cancer
Reduces risk of osteoporosis	Oestrogen taken alone may increase the risk of endometrial cancer

Step 3 Your values: How important are these factors to you?



Step 4 Your leaning

Yes			Unsure		No
HRT					

On balance, you decided

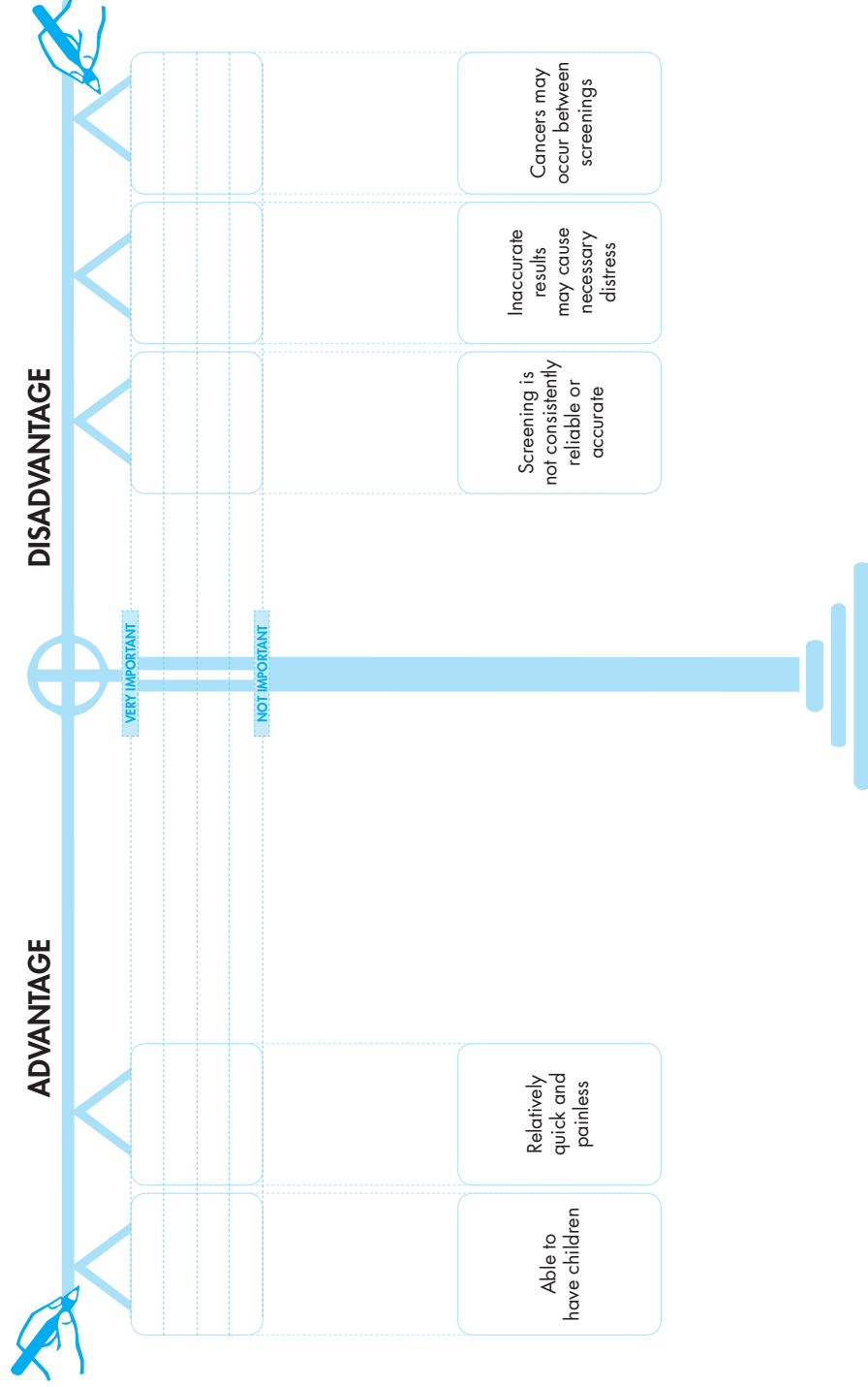
42 Personal Decision Aid Worksheet
SCREENING

Step 1 Briefly review the information in this booklet about managing ovarian cancer risk through screening such as TVU and colour flow Doppler imaging.

Step 2 Possible advantages and disadvantages of screening

Advantages	Disadvantages
Able to have children	TVU is not accurate in distinguishing between benign and cancerous tumours.
Relatively quick and painless	Inaccuracy of tests may result in unnecessary interventions and distress.
	Cancers may occur between screenings.

Step 3 Your values: How important are these factors to you?



Step 4 Your leaning

Yes			Unsure		No
-----	--	--	--------	--	----

Screening

Screening

On balance, you decided

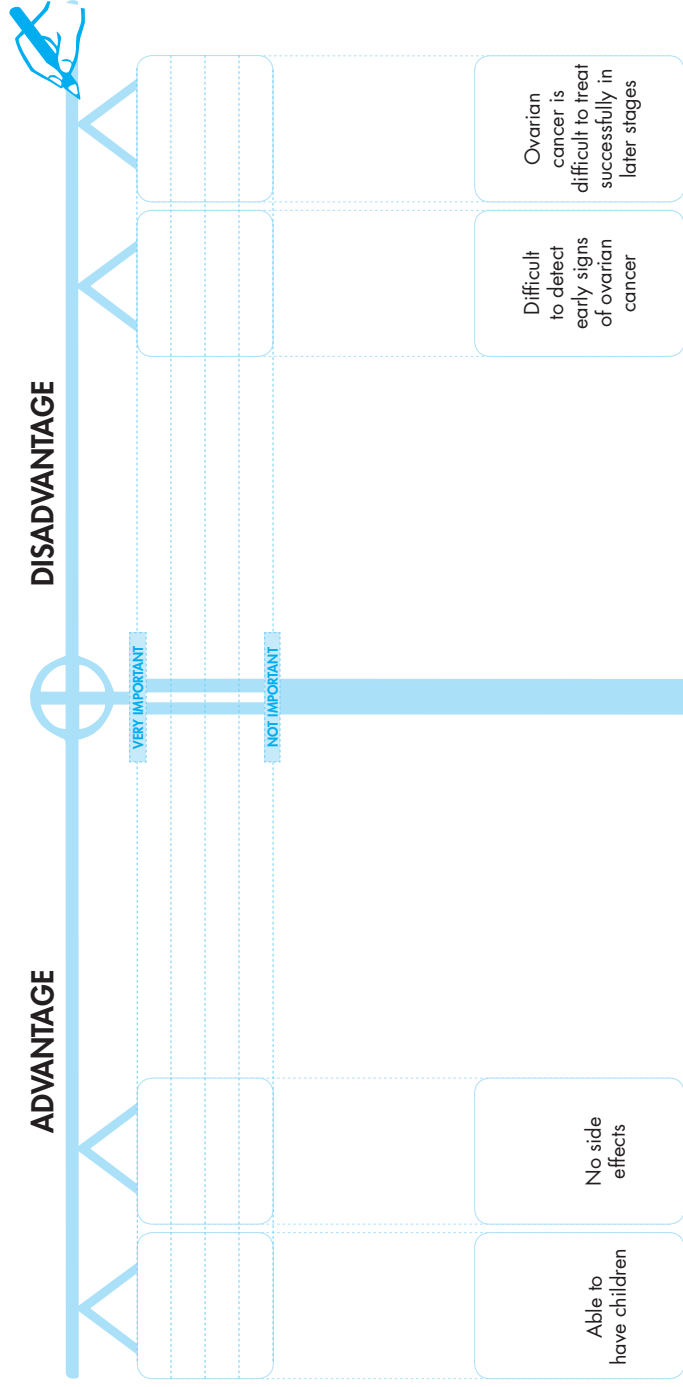
44 Personal Decision Aid Worksheet
WATCHFUL WAITING

Step 1 Briefly review the information in this booklet about managing ovarian cancer risk through watchful waiting.

Step 2 Possible advantages and disadvantages of watchful waiting

Advantages	Disadvantages
Able to have children	The signs and symptoms of ovarian cancer are not easily recognisable during the early stages of the disease.
No side-effects	If ovarian cancer does occur and is only found at an advanced stage it is unlikely to be curable.

Step 3 Your values: How important are these factors to you?



Step 4 Your leaning

Yes			Unsure		No
-----	--	--	--------	--	----

Watchful waiting

Watchful Waiting

On balance, you decided

PERSONAL VALUES CLARIFICATION

BALANCE SHEET

Step 5

Your leaning for each option (you may choose "yes" for more than one option).

RRSO

Yes			Unsure			No
-----	--	--	--------	--	--	----

HRT (for pre-menopausal women considering RRSO)

Yes			Unsure			No
-----	--	--	--------	--	--	----

SCREENING

Yes			Unsure			No
-----	--	--	--------	--	--	----

THE ORAL CONTRACEPTIVE PILL

Yes			Unsure			No
-----	--	--	--------	--	--	----

WATCHFUL WAITING

Yes			Unsure			No
-----	--	--	--------	--	--	----

Step 6 Your decision

WHERE CAN YOU GET

INFORMATION & SUPPORT

You may find it is important to have people you can talk to about your feelings while you're weighing up your options. Your family and close friends may be able to provide the support and understanding that you need during difficult times, and it can also be beneficial to have an independent person to talk to.

There are many types of health professionals who can give you support. These include your general practitioner, genetic counsellor and doctors at a family cancer clinic, your gynaecologist or surgeon.

There are also agencies you can contact – contact details follow.

CONTACT DETAILS

FAMILY CANCER CLINICS AND GENETICS SERVICES

Australian Capital Territory	
Canberra	The Canberra Hospital The Clinical Genetics Department PO Box 11 Woden, ACT 2605 Ph: (02) 6244 2133 Fax: (02) 6244 4625
New South Wales	
Camperdown	Royal Prince Alfred Hospital Department of Molecular and Clinical Genetics Missenden Rd, Camperdown, NSW 2050 Ph: (02) 9515 5080 Fax: (02) 9550 5389
Darlinghurst	St Vincent's Hospital Family Cancer Clinic Victoria Rd, Darlinghurst, NSW 2011 Ph: (02) 8382 3395 Fax: (02) 8382 3386
Kogarah	St George Hospital Hereditary Cancer Clinic Cancer Care Centre Gray St, Kogarah, NSW 2217 Ph: (02) 9113 3815 Fax: (02) 9113 3958
Newcastle and rural outreach services	Hunter Family Cancer Service PO Box 84, Waratah, NSW 2298 Ph: (02) 4985 3132 Fax: (02) 4985 3133
Penrith	Nepean Hospital Clinical Genetics Department PO Box 63, Penrith, NSW 2750 Tel: (02) 4734 3362 Fax: (02) 4734 2567
Randwick	Prince of Wales Hospital Hereditary Cancer Clinic High St, Randwick, NSW 2031 Ph: (02) 9382 2551 Fax: (02) 9382 2588

St Leonards	Royal North Shore Hospital Family Cancer Service St Leonards, NSW 2065 Ph: (02) 9926 6502 Fax: (02) 9926 6433
Westmead	Westmead Hospital Familial Cancer Service Department of Medicine Westmead, NSW 2145 Ph: (02) 9845 6947 Fax: (02) 9687 2331
Wollongong	Wollongong Hospital Wollongong Hereditary Cancer Clinic Illawarra Cancer Care Centre Ph: (02) 4222 5576 Fax: (02) 4222 5793
Queensland	
Herston	Genetic Health Queensland Royal Children's Hospital and District Health Service Herston Road, Herston QLD 4029 Ph: (07) 3636 1686 Fax: (07) 3636 1987
Brisbane	Brisbane North Breast Cancer Family Clinic P O. Box 227, Virginia Business Centre, Virginia, QLD 4041 Ph: (07) 3350 7425 Fax: (07) 3350 5102
South Australia	
North Adelaide	Women's and Children's Hospital Familial Cancer Unit C/- South Australian Clinical Genetics Service 72 King William Rd, North Adelaide, SA 5006 Ph: (08) 8161 6995 Fax: (08) 8161 7984
Tasmania	
Hobart	Royal Hobart Hospital Tasmanian Clinical Genetics Service GPO Box 10611, Hobart, TAS 7001 Ph: (03) 6222 8296 Fax: (03) 6222 7961

Victoria	
Parkville	Royal Melbourne Hospital Family Cancer Centre Grattan St, Parkville, VIC 3050 Ph: (03) 9342 7151 Fax: (03) 9342 4267
Parkville	Royal Children's Hospital Family Cancer Centre C/- Genetic Health Services Victoria Flemington Road, Parkville, VIC 3052 Ph: (03) 8341 6201 Fax: (03) 8341 6390
Melbourne	Peter MacCullum Cancer Institute The Jack Brockhoff Foundation Familial Cancer Centre Locked Bag 1, A'Beckett St Melbourne, VIC 8006 Ph: (03) 9656 1199 Fax: (03) 9656 1539
Clayton	Familial Cancer Centre Monash Medical Centre 246 Clayton Rd, Clayton, VIC 3168 Ph: (03) 9594 2026 Fax: (03) 9594 6022
Western Australia	
Subiaco	Familial Cancer Program King Edward Memorial Hospital, Level 3, Agnes Walsh House, 374 Bagot Road, Subiaco, WA 6008 Ph: (08) 9340 1603 Fax: (08) 9340 1725

Gynaecologists

Ask your GP for a referral to a gynaecologist who specialises in cancer (also called a gynaecologic oncologist).

Menopause clinics

Many public hospitals and women's health centres have menopause clinics. Ask your GP for more information.

Cancer Helpline

This is a free and confidential telephone information service provided by each State and Territory cancer organisation. The national phone number is 13 11 20.

MORE INFORMATION

- *Hormone Replacement Therapy - Exploring the Options for Women*
- *Hormone Replacement Therapy - Making Decisions: Should I use Hormone Replacement Therapy (HRT)*
Both available to download or order at the NHMRC website <http://www.nhmrc.gov.au/publications/synopses/wh35syn.htm>
- *Information for women considering preventive mastectomy because of a strong family history of breast cancer.* Available by phoning the Cancer Helpline in your State or Territory on 13 11 20 or the Centre for Genetics Education on (02) 9926 7324
- *Understanding Hereditary Non-Polyposis Colorectal Cancer.* Available by phoning the Cancer Helpline in your State or Territory on 13 11 20 (toll free).

Ovarian cancer information can also be found on the Internet. Here are some useful websites

OVARIAN CANCER AWARENESS www.ovca.org/index.php

THE CANCER COUNCIL AUSTRALIA www.cancer.org.au

THE CANCER COUNCIL OF VICTORIA www.cancervic.org.au

THE CANCER COUNCIL NSW www.cancercouncil.com.au

THE CANCER COUNCIL OF SOUTH AUSTRALIA

www.cancersa.org.au/asp/asp/home.aspx

THE CANCER COUNCIL OF TASMANIA www.cancertas.org.au

THE CANCER COUNCIL WESTERN AUSTRALIA www.cancerwa.asn.au

GYNAECOLOGICAL CANCER SOCIETY OF QUEENSLAND

www.gcsau.org

NATIONAL BREAST CANCER CENTRE www.nbcc.org.au

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Family cancer clinic staff

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The information in this booklet is current at the date of production. Please check with your doctor or genetic counselling service for any new information.

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GLOSSARY

Ashkenazi Jews A population of Jews descended from Central and Eastern Europe.

Benign Not malignant (non-cancerous).

Bilateral risk-reducing salpingo-oophorectomy (RRSO) Surgery to remove both ovaries and fallopian tubes before a cancer has occurred in order to prevent the possible development of cancer.

BRCA 1 and BRCA 2 'Cancer protection' (tumour suppressor) genes. Inherited mutations in these genes confer a predisposition (increased risk) to breast and ovarian cancer by making the gene faulty.

CA 125 A protein found in the blood. Increased levels of this protein may indicate the presence of ovarian cancer.

Cancer The result of uncontrolled cell division and growth. Cancer occurs when cells in a part of the body become abnormal due to a build-up of changes in the genes that usually control how the cell divides and grows. Cancer cells have the ability to spread to other parts of the body.

Clinical Geneticist Doctors with specialist training in clinical genetics. Their role is in diagnosis, management and the provision of genetic counselling and appropriate genetic testing for individuals or families with concerns about a genetic condition that may run in their family.

Colour flow Doppler imaging A system used in combination with ultrasound that allows the operator to see blood flow.

Coronary heart disease Also called coronary artery disease. Due to narrowing or blockage of the vessels that supply blood to the heart as a result of a build-up of cholesterol or other fats in the blood.

DNA Chemical that makes up the genes and chromosomes.

Endometrium A membrane lining the uterus.

Endometriosis A condition where endometrial-like tissue grows outside the uterus.

Epithelium A layer of cells (skin) covering certain internal and external surfaces of the body.

Epithelial ovarian cancer Cancer of the ovary arising in the epithelium (the 'skin' or outer cells) covering the ovary.

Fertilisation The fusing of an egg and sperm at conception to create an embryo.

Fibroid A benign tumour which grows from the muscle layers of the uterus.

Gastrointestine A multi-organ system that digests food, extracts nutrients and energy and expels waste.

Gene The basic unit of heredity; a segment of DNA which contains the information for a specific characteristic or function.

Genetic counselling The provision of diagnosis, information, risk assessment and support for individuals or families with concerns about a genetic condition that may run in their family.

Genetic counsellor A health professional with specialist training in genetics and counselling who can provide information and support to individuals or families with concerns about a genetic condition which may run in their family.

Gynaecologic oncologist A doctor specialised in obstetrics and gynaecology with training in gynaecological cancer care.

Hereditary non-polyposis colorectal cancer (HNPCC)
Also known as Lynch syndrome. A familial cancer syndrome associated with increased risk for certain cancers, including bowel, endometrial and ovarian cancers.

Hormone replacement therapy (HRT) A treatment used to replace the hormones produced naturally before menopause to reduce the effects of menopause.

Hysterectomy Surgical removal of the uterus (womb).

Laparoscope A flexible tube which has a light and optical system for viewing inside the abdomen.

Laparoscopy A surgical technique that uses small incisions in the abdomen and a laparoscope.

Laparotomy A surgical technique where an incision is made in the abdomen to access the abdominal contents

Mutation A permanent change in a gene that makes it faulty.

Malignant Cancerous.

Menopause The cessation of periods. This can occur naturally or as a result of surgery or other treatments.

Mismatch repair genes A group of genes that repair damaged DNA.

Oophorectomy Surgery to remove the ovaries. It may be bilateral (both ovaries) or unilateral (one ovary).

Ovarian cancer Cancer of the ovary.

Ovary Part of the female reproductive system containing eggs (ova).

Ovulation The release of an egg from the ovary each month.

Salpingo-oophorectomy
Surgical removal of the fallopian tube and ovary.

Screening Testing of individuals with no symptoms of a particular disease or condition to determine whether the disease or condition is present or not.

Surgical menopause Menopause induced by the surgical removal of the ovaries.

Syndrome A group of characteristics and/or symptoms that occur together in a recognisable pattern.

Tamoxifen A medication used to treat and/or prevent breast cancer.

The oral contraceptive pill (The Pill)
A drug taken orally used to protect against pregnancy by preventing ovulation.

Transvaginal ultrasound (TVU)
Use of sound waves to detect changes to internal organs through a device inserted into the vagina.

Tubal ligation Tying of the fallopian tubes to prevent pregnancy.

Uterus (womb) The female reproductive organ in which the fetus develops into a baby over a period of nine months.

