HOW DO I MANAGE THE RISK OF DEVELOPING OVARIAN CANCER

A Decision Aid

A decision aid about ovarian cancer risk management for women at risk of developing ovarian cancer due to gene changes

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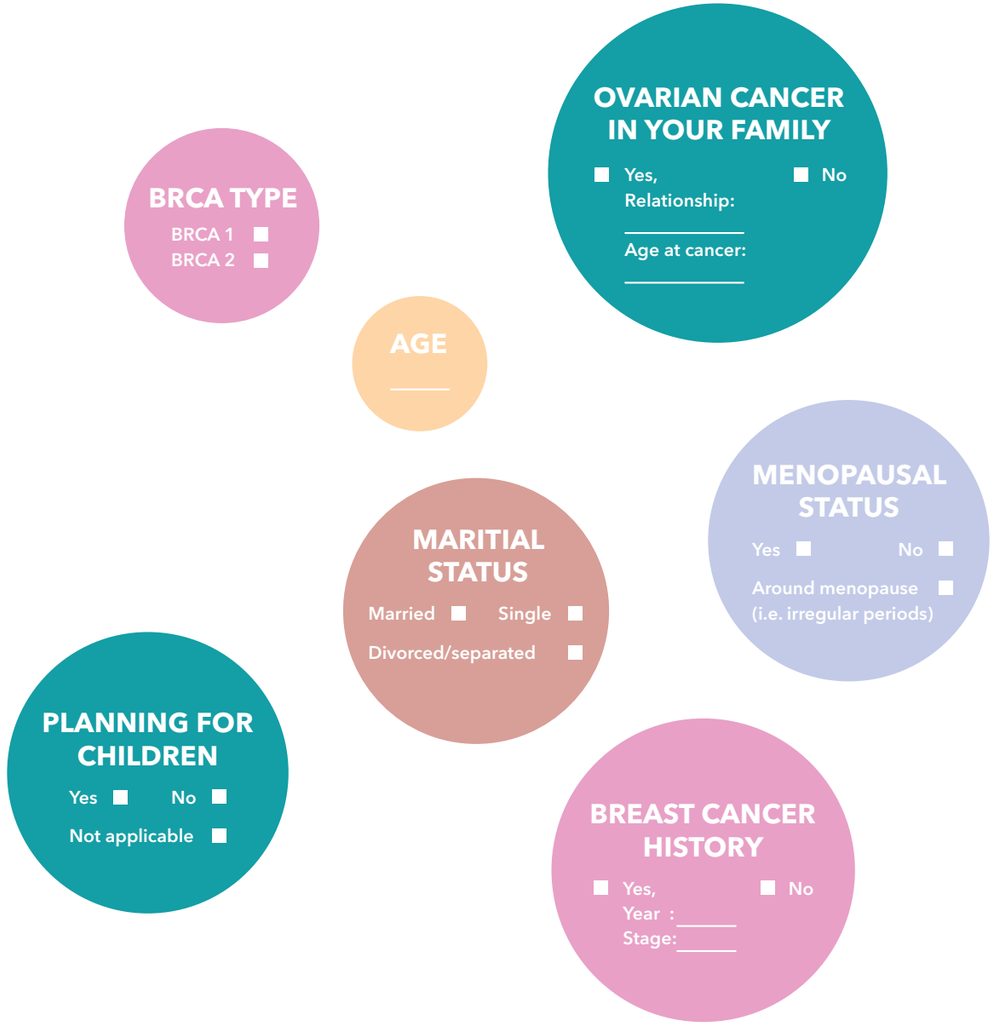
WHY HAVE YOU BEEN GIVEN THIS BOOK?

This book is for women who are at high risk of developing ovarian cancer due to an inherited faulty BRCA gene

How will this book help you?

- This book provides useful information when deciding how to manage the risk of developing ovarian cancer.
- There are no right or wrong decisions. This book will help you address the areas that matters most to you, and to encourage discussion with your doctor to reach a decision that best suits your needs.
- You can also write down any questions you would like to ask your doctor in this book, so you can bring it along with you when meeting with your doctor to discuss further.
- This book is not designed to replace consultation with your doctor.



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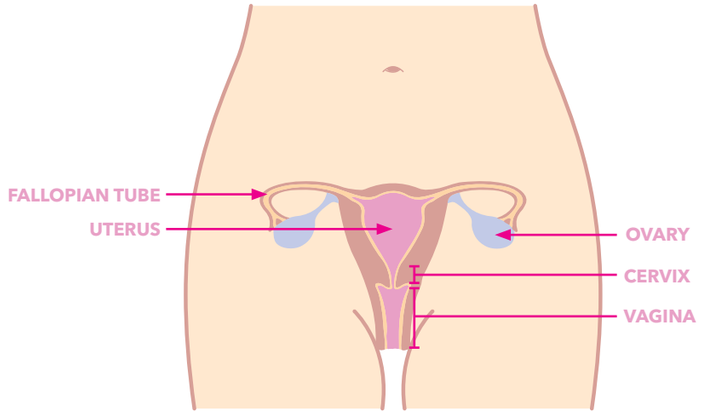


Figure 1: The female reproductive system

What are ovaries?

Ovaries are a pair of organs that are part of the female reproductive system (see Figure 1). An ovary is about the size of an almond (1x2x3cm), located on each side of the uterus (womb).

SECTION 1: ABOUT OVARIAN CANCER

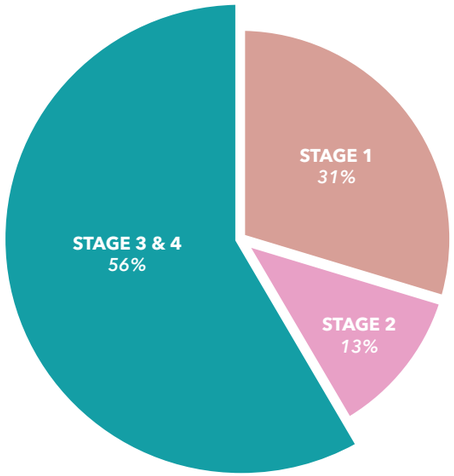
SECTION 1: INFORMATION ABOUT OVARIES, OVARIAN CANCER, AND BRCA GENE

Each ovary serves as an 'egg factory' that is responsible for producing eggs (ova) as well as female hormones called oestrogen and progesterone.

Ovarian cancer often goes undetected until the late stage because the symptoms are not easily recognisable.

SECTION 1: ABOUT OVARIAN CANCER

Figure 2: Stage of diagnosis of ovarian cancer in Malaysia (2007-2011)



What is ovarian cancer?

Ovarian cancer is the 4th most common cancer found in Malaysian women[1]. In Malaysia (2007-2011)[1], amongst the reported ovarian cancer cases:

- 31 % were diagnosed at stage 1
- 13 % at stage 2
- 56 % at stage 3 and 4 (the late stages)

Late-stage ovarian cancer is much more difficult to treat and is frequently difficult to cure.

Stages, symptoms and treatment of ovarian cancer are illustrated in Figure 3a, 3b, 3c, 3d.

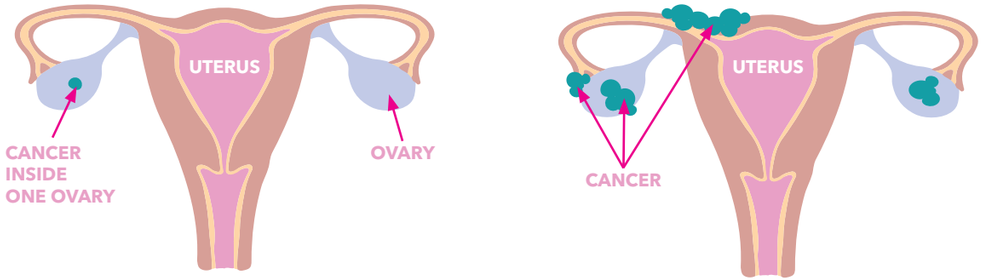


Figure 3a: Early stages of ovarian cancer

Stage 1

Cancer inside ovary or fallopian tube.

Stage 2

Cancer has spread from ovaries to area within hip bone (uterus/colon/pelvic peritoneum/bladder).

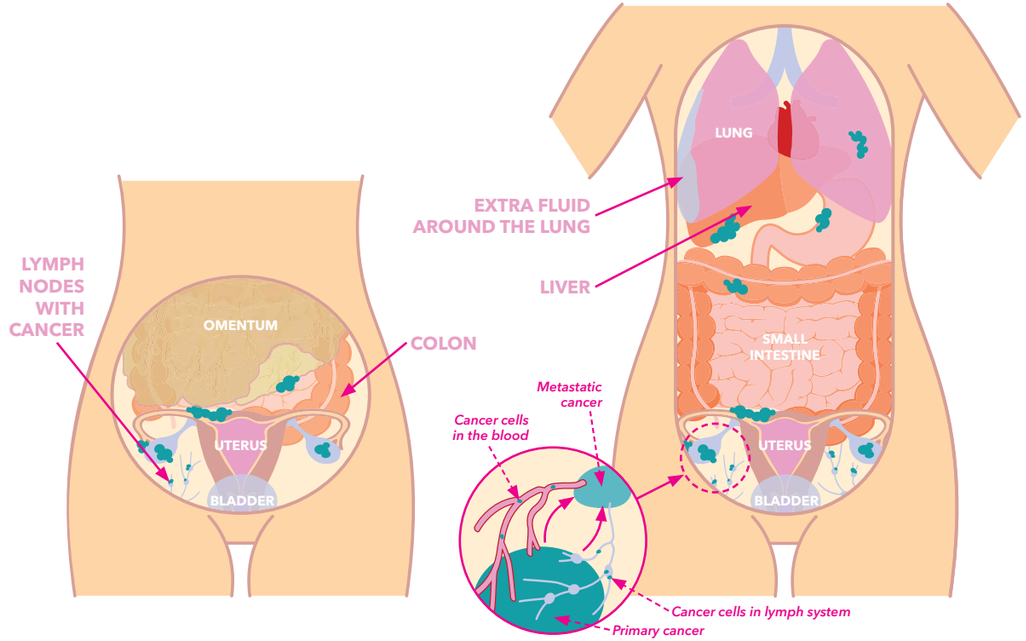


Figure 3b: Later stages of ovarian cancer

Stage 3

Cancer has spread beyond the pelvis to nearby lymph nodes/peritoneum/omentum.

Stage 4

Cancer has spread beyond abdomen to other parts of the body. Extra fluid build up around the lungs.

SYMPTOMS

Breathless when lying flat

However, early stage ovarian cancer often shows no symptoms

TREATMENTS

SURGERY

- Removal of uterus, fallopian tubes, ovaries, and omentum (fatty tissues along the large intestine)
- Removal of ovary, fallopian tubes, and omentum (for fertility conservation in young patient with early stages of cancer)

Chemotherapy may or may not be given after surgery

Figure 3c: Symptoms and treatments of early stage ovarian cancer

SYMPTOMS

COMMON SYMPTOMS[2-3]

- Persistent bloated feeling (lower part of abdomen)
- Easily feel full when eating and/or loss of appetite
- Abdominal pain/ Pelvic discomfort (below tummy area)
- Unexpected urinary problem (e.g. frequent urination)

OTHER SYMPTOMS[2-3]

- Changes in bowel habits (e.g. constipation and diarrhea)
- Extreme fatigue
- Unexplained weight loss
- Unusual vaginal bleeding and discharge
- Pain during intercourse

TREATMENTS

SURGERY

- Removal of uterus, fallopian tubes, and ovaries
- Removal of omentum and tumour nodules
- Some parts of the intestine, bladder or liver may be removed depending on where the cancer has spread

Chemotherapy and targeted therapy

Figure 3d: Symptoms and treatments of late stage ovarian cancer

Why are you at risk of developing ovarian cancer?

The **BR**east **CA**ncer (BRCA) gene is present in every human. This gene produces substances (or proteins) that prevent cancer cells from forming. Thus, the BRCA gene is also known as a 'tumour suppressor gene'.

Women with a faulty BRCA gene are known as 'BRCA carriers'. Changes in your BRCA gene can lead to a faulty protein that cannot function properly to suppress cancer in your body. Therefore, this places you at high risk for developing ovarian cancer.

Figure 4 shows how changes in genes can lead to ovarian cancer.

Changes in your BRCA gene can lead to a faulty protein that cannot function properly to suppress cancer in your body

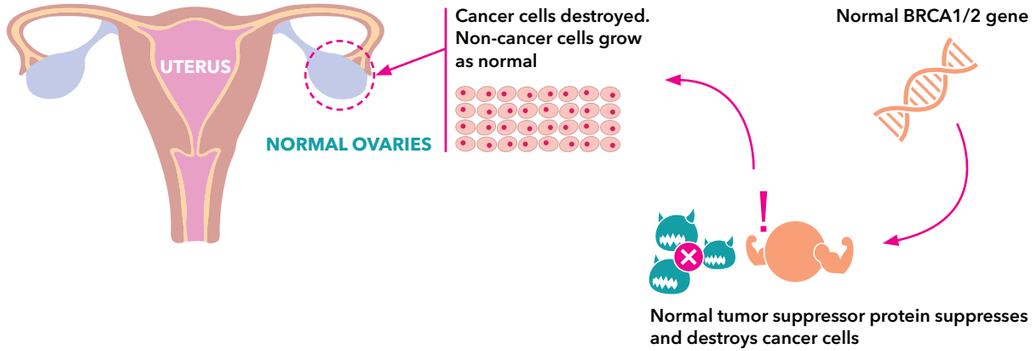


Figure 4a: Normal BRCA gene produces functional and active tumour suppressor protein that prevent ovarian cancer

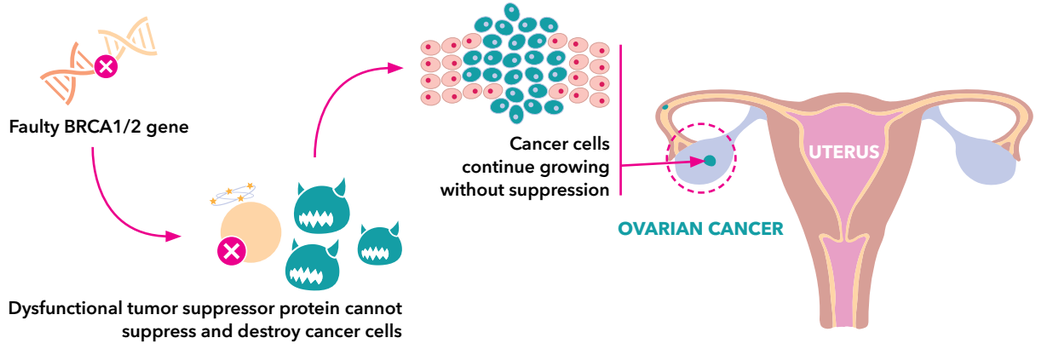


Figure 4b: Faulty BRCA gene produces dysfunctional tumour suppressor protein leading to ovarian cancer

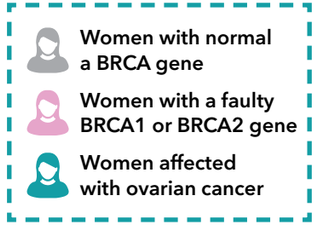
Knowing whether you are a BRCA gene carrier will help you manage the risk and safe-guard against developing ovarian cancer

What is the risk of developing ovarian cancer if you have the faulty BRCA1 or BRCA2 genes?

The lifetime risk (possibility to happen in a person's lifetime) of developing ovarian cancer in women with normal BRCA gene is less than 2 in 100[4] (refer Figure 5). The ovarian cancer risk in women with the faulty BRCA1 (44 in 100) and BRCA2 (17 in 100) genes by the age of 80 is shown belowon the next page[5].

Despite the high-risk, having this faulty gene does not necessarily mean that you will develop ovarian cancer.

Figure 5*: Risk of ovarian cancer in women with normal and faulty BRCA1/2 genes



***Note:**

This risk information is based on research done in European populations. There is still not enough information for Asians. Studies to date suggest the risks are likely to be lower in Asians.

SECTION 2: WHAT CAN I DO TO MANAGE MY RISK OF DEVELOPING OVARIAN CANCER?

Removing the ovaries is the only proven method to reduce the risk of ovarian cancer

Despite this strong recommendation to remove your ovaries, your concerns and personal issues are very important to be considered and discussed *because removing the ovaries can affect women quite significantly*

Removing the ovaries and fallopian tubes is the only proven method to reduce the risk of ovarian cancer, although some BRCA gene carriers prefer other non-surgical strategies, such as:

1. Ovarian screening
2. Birth control pill and tubal ligation
3. Other strategies: being aware of your body, lifestyle modification and meditation

Importantly, these strategies **DO NOT** reduce the risk of developing ovarian cancer.

A brief overview of these options is provided in the diagram at the side.

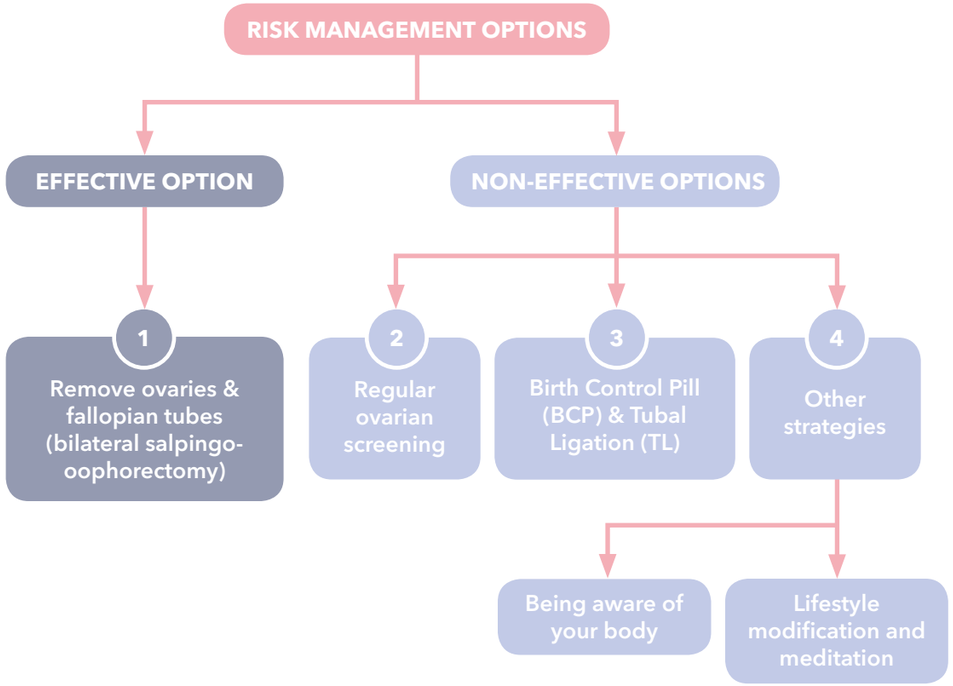


Figure 6: Options to manage ovarian cancer risk

Comparing the risk management options

	BRIEF DESCRIPTION	REDUCE OVARIAN CANCER RISK	IS THIS OPTION RECOMMENDED BY THE MEDICAL GUIDELINE?	EFFECT ON BREAST CANCER RISK	FEELING RELIEF FROM ANXIETY ABOUT CANCER	BECOME MENOPAUSAL	MENOPAUSE SIDE-EFFECTS (e.g. Hot flashes, long-term health risk)	CAN I STILL DEVELOP OVARIAN CANCER?
1 REMOVE BOTH OVARIES AND FALLOPIAN TUBES	The procedure of removing the non-cancerous ovaries and fallopian tubes. *(Refer to page 29)*	Reduced (up to 80%[7, 8])	Yes (it is the only option recommended in most medical guidelines)	Reduced in BRCA2 carrier (if ovaries are removed before the age of 50[12])	Many feel relief from cancer worry following the surgery[13]	Menopause starts immediately with removal of ovaries and will result to being infertile	Varies, although sudden menopause can be more severe than natural menopause[15]	Small remaining risk of peritoneal cancer but very uncommon[16]
2 REGULAR OVARIAN SCREENING	Annual screening using: • Transvaginal ultrasound (TVUS) • Blood test CA125 *(Refer to page 43)*	No	No (ovarian screening has been proven as ineffective)	Not applicable	Normal finding from screening may give you a false sense of relief[14]	Natural menopause typically starts around the age of 50 years	The impact of natural menopause varies in different individuals	Risk of ovarian cancer remains high
3 BIRTH CONTROL PILL (BCP) AND TUBAL LIGATION (TL)	**BCP** taking hormone pill to prevent pregnancy. **TL** having the fallopian tubes tied and cut off. *(Refer to page 47)*	Reduced: **BCP** about 50%[8-10] **TL** about 34%[11]	No	BCP may increase the risk of breast cancer[9]	No information	Natural menopause typically starts around the age of 50 years	The impact of natural menopause varies in different individuals	The risk is moderately high
4 OTHER STRATEGIES	When you chose not to do anything with your ovaries such as: • Being aware of your body • Healthy lifestyle and meditation *(Refer to page 49)*	Less Evidence	No	Not applicable	Depends on the individual	Natural menopause typically starts around the age of 50 years	The impact of natural menopause varies in different individuals	Risk of ovarian cancer remains high

SECTION 2: RISK MANAGEMENT

1 Removing the ovaries and fallopian tubes

Bilateral salpingo-oophorectomy is the procedure where you remove the noncancerous ovaries and fallopian tubes to reduce the risk of developing cancer.

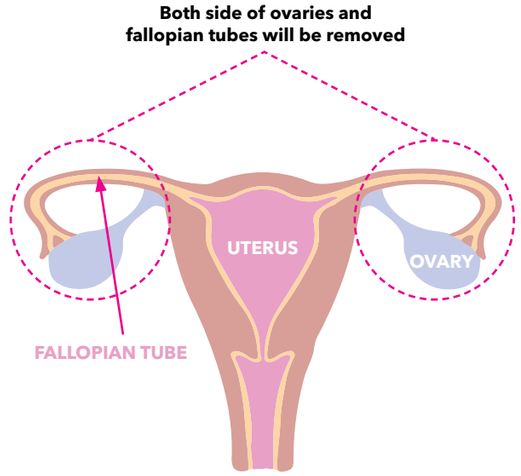


Figure 7: Bilateral salpingo-oophorectomy

Ovaries and fallopian tubes removal have become the universal standard and recommendation given by doctors to women with a faulty BRCA gene[17].

According to the medical evidence, removing the ovaries and fallopian tubes is strongly recommended due to the following reasons:

Main reasons for strong recommendation for removing the ovaries of BRCA gene carriers

HARD TO DETECT

Ovarian cancer is hard to detect. Till now, there is no available reliable method to detect ovarian cancer at an early stage[18-20].

SYMPTOMS ARE VAGUE

Symptoms of ovarian cancer are vague and easily confused with other conditions such as irritable bowel syndrome. Therefore, detecting ovarian cancer early enough often fails[21].

LOW SURVIVAL RATE

There is a low survival rate in patients with late stage ovarian cancer[21, 22].

THE ONLY PROVEN METHOD

Ovarian screening using blood test tumour marker CA125 is not reliable. Only 20% of early stage ovarian cancer has raised tumour marker CA125 in blood test[23-24].

When is it advisable to remove the ovaries?

Typically, BRCA1 gene carriers are advised to remove their ovaries and fallopian tubes between the ages of 35 to 40 or upon completing childbearing[17]. This is because ovarian cancer risk begins to increase sharply from the age of 40[5].

For a BRCA2 carrier, it is reasonable to delay removal of the ovaries until the age of 40-45 years because the onset of ovarian cancer in BRCA2 carriers is on average 8-10 years later than in BRCA1 carriers[16, 17].

between the ages of 35 to 40 or upon completing childbearing

What happen if you delay removal of ovaries?

The ovarian cancer risk continues to increase as women get older, regardless of menopause[5,16].

What is the risk of developing ovarian cancer after removing the ovaries?

Removing the ovaries and fallopian tubes will reduce the risk of developing ovarian cancer and fallopian tube cancer by about 80%[6, 7].

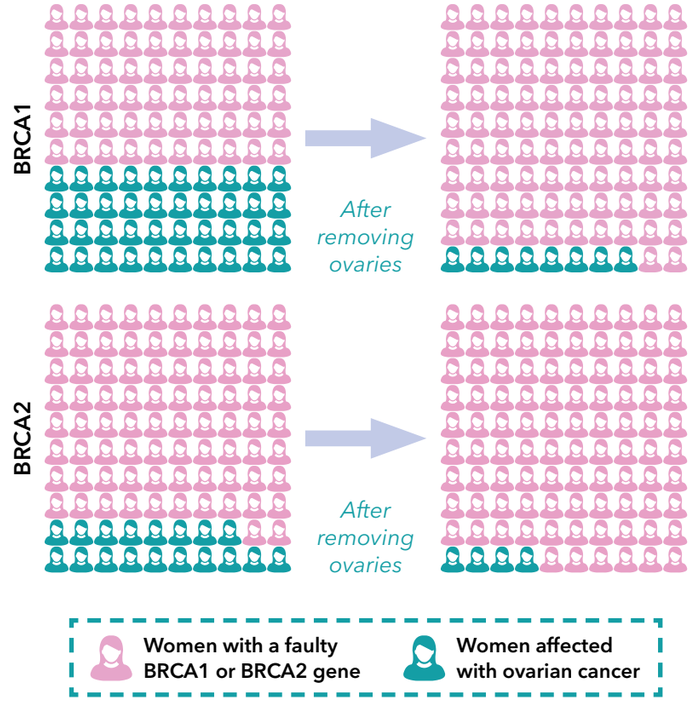


Figure 9: Risk of ovarian cancer in BRCA carriers after ovaries have been removed

Reduction of breast cancer risk in BRCA2 carriers

Two studies suggest that removing ovaries before the age of 45 will reduce the risk of breast cancer in BRCA2 carriers[12-13].

Studies are still ongoing to obtain more conclusive result regarding the risk-reduction of breast cancer after removing ovaries in BRCA mutation carriers[13,14].

Peritoneal cancer risk after removing the ovaries

The peritoneum is the thin tissue that lines the wall of the ovaries and pelvic cavity and it cannot be removed by surgery.

In 100 women who had their ovaries removed, about 1 to 4 women may still develop peritoneal cancer[27-29].

About 1 to 4 women may still develop peritoneal cancer

Reducing risk of death

Removing ovaries and fallopian tubes can reduce the risk of death including BRCA carriers with history of breast cancer[18,30].

Advantages of keyhole surgery

The operation involves small incisions.

It minimises pain, bleeding, and will have minimal scars.

Faster recovery, able to return to normal activities several days after surgery.

What is the procedure to remove the ovaries?

Keyhole surgery (also called laparoscopic surgery) is typically used to remove non-cancerous ovaries.

Under general anaesthetic, three small incisions (about 5-12mm) on the abdomen are made (see Figure 11).

The doctor will then insert a laparoscope, which is a small instrument with a camera, through the incision to help remove both ovaries and fallopian tubes.

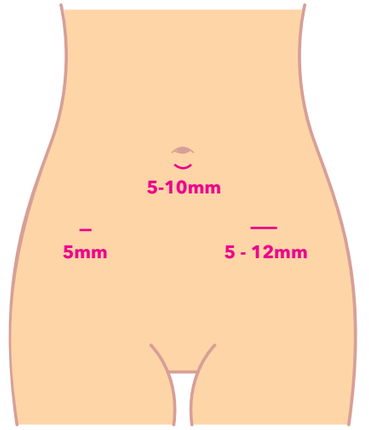


Figure 11: Incisions of keyhole surgery

The site of incisions is depending on the surgeon. If any previous abdominal surgery done, keyhole surgery may not be suitable if you have undergone previous surgery in the abdominal area.

If this is the case, the doctor will examine and assess if conventional open surgery is necessary and explain any associated risk.

HOW LONG WILL THE SURGERY TAKE?	HOW LONG WILL THE HOSPITAL STAY BE?	WHAT IS THE RECOVERY TIME	COST
About 30-45 minutes (or about 2-5 hours if combined procedure with breast removal)	Can leave the hospital on the same day, or on the next day (if there are no signs of infection or complication)	About 1 week to resume normal activities	Range cost of keyhole surgery: • **PPUM** RM1000-RM2000 • **Government hospital** RM50 (third class)-RM1200 (first class) • **Private hospital** RM13000-RM14000

WHAT ARE THE SURGERY RISKS?

MINOR COMPLICATIONS	MAJOR COMPLICATIONS
Occurs in one (1) or two (2) cases in each 100 surgeries performed[29]	Rare and occurs in one (1) in every 1,000 cases[31]
Examples	*Examples*
infection (e.g. skin, bladder), minor bleeding or bruising at the point of incision, feeling nauseas and vomiting	damage to nearby organs, damage to a major artery, complication due to carbon dioxide from procedure, allergic reaction to anaesthesia, deep vein thrombosis (blood clot in blood vessel, usually in the leg) and pulmonary embolism (blockage of blood vessel in lungs)

Do I need to remove my uterus?

Removing the uterus is not usually recommended because the faulty BRCA gene is not associated with cancer of the uterus.

However, uterus removal is common amongst carriers who use tamoxifen for breast cancer treatment. Tamoxifen may promote the thickening of the uterus wall's lining which possibly associated with uterine cancer.

Do I need additional follow-up(s) after surgery?

The doctor will see you about two weeks following the surgery to check the wound and check on your condition.

If you were not menopausal before the surgery, the doctor will assess you for any symptoms of post-surgical menopause.

You will be further advised to seek an annual examination due to the small residual risk of peritoneal cancer.

The effects of sudden menopause and the duration of the menopausal symptoms vary in each individual.

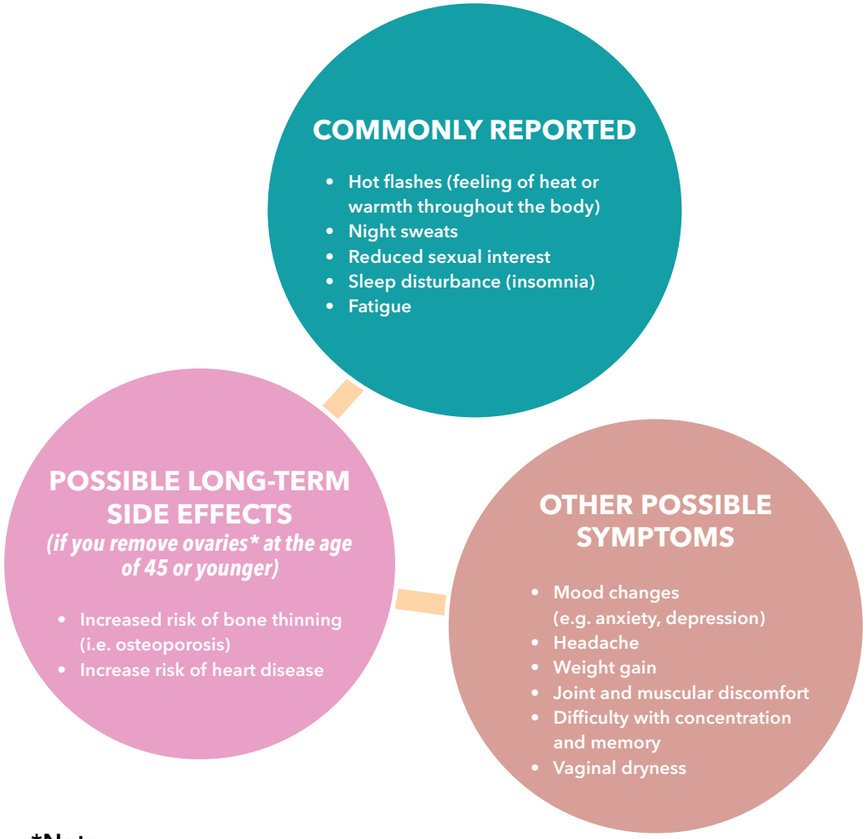
What to expect after removal of ovaries?

1. You will become menopausal (menstrual period will permanently stop).

2. You cannot get pregnant.

For those who have menopause, these issues might not be relevant.

Figure 12 on the next page lists the possible side effects women may experience[15, 17, 32]. Hot-flushes, fatigue, joint and muscular discomfort symptoms are common amongst Malaysian women[33].



***Note:**

In the next page, we provide stories of Malaysia BRCA carriers' experience with menopause. Discuss with your doctor if you want to talk to other BRCA carriers who have removed their ovaries.

Figure 12: Menopausal symptoms

Below are some stories of Malaysia BRCA carriers' experience with menopause. Discuss with your doctor if you want to talk to other BRCA carriers who have removed their ovaries.

EXPERIENCE WITH THE MENOPAUSE

I removed ovaries when I still considered young (aged 38) with a regular period. However, I didn't experience any serious menopausal symptoms. But I understand that women experience menopause differently. I am grateful that I didn't have any severe symptoms after I remove the ovaries.

HOW I FEEL AFTER MY OVARIES REMOVED

I think nothing much has changed. It's kind of easy too that I don't need to deal with menstruation anymore.

Now that I have lost my ovaries, I do feel a bit sad at the beginning after the surgery. But I overcome that thought with positive thinking that at least now I don't need to feel worried about developing ovarian cancer anymore.

Madam L, Chinese, BRCA1

SECTION 2: RISK MANAGEMENT

CONCERN ABOUT CHEMOTHERAPY

I removed ovaries at a young age (aged 38). The side effects didn't come to me immediately, but a few months later. I had joint and muscle pains, but I'm not quite sure if this is directly related to sudden menopause from ovaries removal.

I talked with the doctor and they gave me medication to overcome this. But later, I feel like my appetite increased and I always feel hungry especially at night. I do put on weight too. I suspected it may be related to the medication. So now, I decided to deal with it through an active and healthy lifestyle. I take care of my diet and exercise regularly. I still had hot-flash but it comes and goes.

These side effects are troublesome, but I wanted to face it positively. The side effect I'm facing might be terrible but there might be people who face it more severe than me

HOW I FEEL AFTER MY OVARIES REMOVED

I just take it positively and accept that this is from God. I accepted the good and bad with an open heart. I think the thing I most appreciate after removing the ovaries is, I no longer have a menstrual period, so I can pray and focus more on the act of worship

Madam N, Malay, BRCA1

What can you do to manage the menopausal symptoms?

Menopausal management depends on your situation (e.g. age, the severity of symptoms, previous history of cancer). Some options to manage menopausal symptoms are explained below:

a) Non-hormonal medication

The need for non-hormonal medication depends on how troublesome your menopausal symptoms are[34]. You should discuss with your doctor if the options listed below are suitable for you.

MENOPAUSAL SYMPTOMS	OPTIONS FOR MANAGEMENT
Hot-flashes	Non-hormonal medication such as antidepressant and blood pressure medication.
Vaginal dryness	Vaginal moisturisers and lubricants.
Mood swings	Antidepressant medicine.
Bone thinning (osteoporosis)	Raloxifene, calcium, Vitamin D
Sleep disturbance	Short term use of sleeping medication.

b) Lifestyle changes

Some studies have shown that lifestyle modifications such as exercise and diet can help women overcome menopausal symptoms[35-36].

Physical activity such as exercise and yoga may help to improve psychological health (e.g. mood changes and swings) and relieve mild symptoms, such as hot flashes and sleep disturbance[36-38].

SECTION 2: RISK MANAGEMENT

c) Short-term Hormone Replacement Therapy (HRT)

HRT involves the use of oral medication, patches or implants that contain hormones to replace the sudden loss of hormones from the surgery.

Short-term HRT can be considered **for women without breast cancer** who have had their ovaries removed at the age of 45 or below. Some advantages and disadvantages of HRT are listed below:

ADVANTAGES	DISADVANTAGES
Relieve symptoms: Hot-flashes, night sweats and sleep disturbance (insomnia) *Reduce risk of:* Bowel cancer, bone fractures	*Increase risk of:* Breast cancer (*see note), stroke, breast tenderness, spotting or return of periods, abnormal mammogram screening, blood clots

*note:

The use of short-term HRT (2-3 years after surgery) poses no apparent increase in risk of breast cancer in BRCA gene carriers aged below 50 years with no history of breast cancer[39, 40].

The need for HRT also depends on how troublesome the menopausal symptoms are. You can discuss this further with your doctor as to whether short-term HRT is necessary and suitable for you.

2 Regular ovarian screening

Ovarian screening aims to detect cancer as early as possible before any symptoms appear and for the treatment to increase the chance of cure. Ovarian screening includes:

- Transvaginal ultrasound (TVUS): an internal examination using an ultrasound instrument to see any abnormality of the ovary and related organs.
- Blood test to measure the blood level tumour marker CA125.

Routine ovarian screening is not usually offered to BRCA gene carriers due to its inaccuracy based on established scientific evidence

FAILURE TO DETECT CANCER AT AN EARLY STAGE	DOES NOT REDUCE THE CHANCE OF DEATH	NORMAL FINDING FROM SCREENING IS NOT RELIABLE	NORMAL FINDING FROM SCREENING CAUSES FALSE SENSE OF SECURITY
Many studies have proven that ovarian screening is not reliable because it often fails to detect ovarian cancer at an early stage[20-22].	Ovarian cancers in screened women are mostly found at advanced stages[26].	Ovarian cancer are found in women even when CA125 levels are normal[25, 26].	Normal findings from ovarian screening may cause a false sense of relief about the effectiveness of ovarian screenings[16].

Figure 13: Disadvantages of ovarian screening

For the reasons described above, ovarian screening is not usually offered to BRCA gene carriers.

Although the standard recommendation is not to conduct ovarian screening, some doctors may still offer screening as an option, or you may choose to have the screening. Therefore, it is important that you be fully aware of the disadvantages of ovarian screening as listed above.

The size of the ovaries and fallopian tubes are very small. Apart from their position deep inside the middle section of the body, they are also surrounded by larger organs

Why is it difficult to detect ovarian cancer using ovarian screening?

- The size of the ovaries and fallopian tubes are very small.
- Apart from their position deep inside the middle section of the body, they are also surrounded by larger organs such as the uterus, bladder and rectum (see Figure 14).
- During an external physical examination, it may **not be possible for a doctor to feel the ovaries.**
- Abnormal blood levels of CA125 will only be detected in advanced ovarian cancer[25,26].

*Note: Undergoing **a Pap smear cannot detect ovarian cancer**. A Pap smear procedure is performed for cervical cancer screening.*

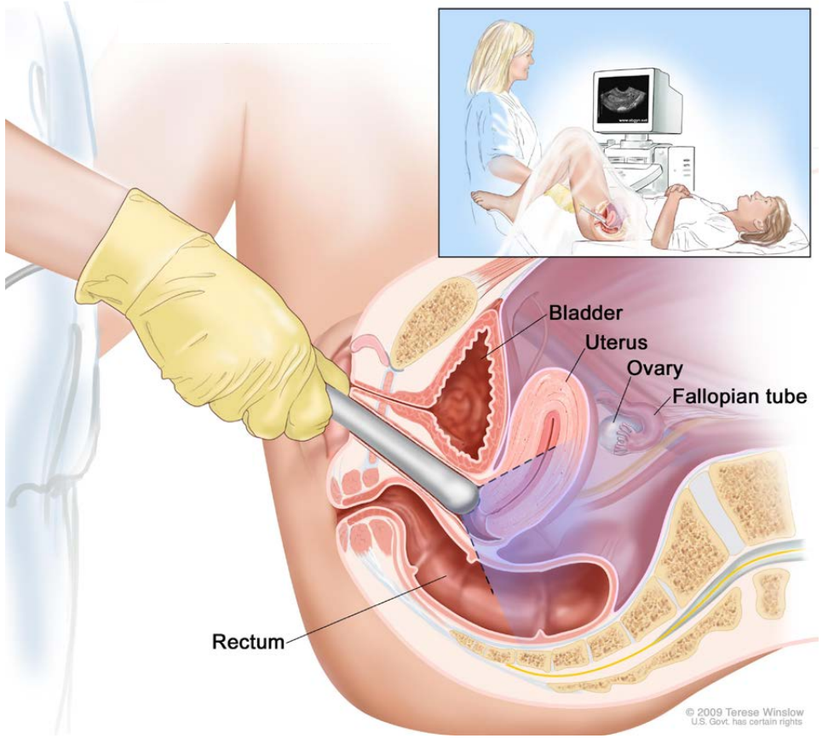


Figure 14: Transvaginal ultrasound

3 Birth control pill and tubal ligation

Birth control pill and tubal ligation can help reduce the risk of ovarian cancer. However, these strategies are not recommended solely for ovarian cancer prevention.

Birth control pill

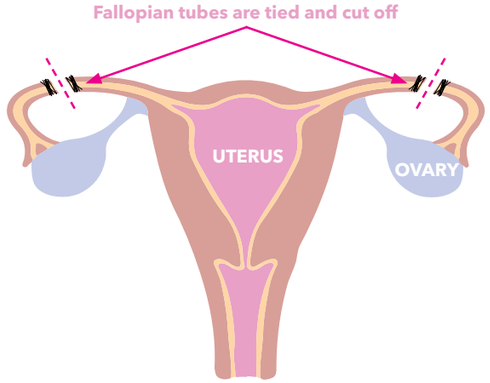
Also known as oral contraception, it means taking a hormone-containing pill to prevent ovaries from producing eggs.

Studies showed 10-years cumulative use of birth control pill can reduce 50% risk of ovarian cancer in BRCA carriers[9, 10].

However, birth control pills are not usually recommended because some studies show that it also increased risk of breast cancer especially in BRCA1 carriers below the age of 40[9, 10, 19].

Birth control pill and tubal ligation are not recommended solely for ovarian cancer prevention

SECTION 2: RISK MANAGEMENT



Tubal ligation

Tubal ligation means having the fallopian tubes tied and cut off. This is usually done by women for birth control.

Some studies show that tubal ligation have some protective effect against ovarian cancer in BRCA carriers, especially those with BRCA1[11, 32].

Current available scientific evidence is not strong enough to support tubal ligation as standard recommendation to reduce the risk of ovarian cancer in BRCA carriers[11, 32].

4 Other strategies

a) Being aware of your body

'Being aware of your body' means that you refrain from doing anything at this stage to the ovaries but instead monitor for any changes in your body.

- Early stage ovarian cancer (stage 1) does not always produce symptoms (list of symptoms in Figure 3).
- Symptoms are vague and often easily confused with other conditions such as irritable bowel syndrome (IBS).
- A common presentation of early ovarian cancer such as abdominal discomfort or mass in abdomen.
- Symptoms related to the spread of cancer to other organs such as a cough (spread to lungs), losing weight/appetite (liver), increased bone pain (bones), other lumps in the lymph nodes in the neck or armpit or the occurrence of headache (brain).
- Symptoms are difficult to be immediately recognised by the doctor as related to ovarian cancer. Thus, ovarian cancer is often found at a later stage when is it harder to treat.

Early stage ovarian cancer (stage 1) does not always produce symptoms

However, there is no evidence to suggest that these strategies can reduce the risk of developing ovarian cancer in women who are at high-risk due to the faulty BRCA gene

b) Lifestyle modification

The examples of lifestyle modification: regular exercise, healthy diet, Ayuverdic diet, not smoking, etc.

Although not specific to ovarian cancer prevention for women with the faulty BRCA gene; healthy diet, active lifestyle and maintenance of the ideal body weight may help to improve overall health and reduce the overall chance of developing cancer[41-43].

c) Specific meditation and prayers

For example: mindfulness, spiritual therapies, Islamic Quranic healing using incantation (Ruqyah)

Some women opt for a spiritual or religious approach such as meditation[38] and Islamic Quranic healing using incantation (Ruqyah) and benefit in term of relief from anxiety about cancer[44].

Women may experience both positive and negative emotions either after removal of their ovaries, or if they choose to keep their ovaries

Emotional impact: what you may feel if you have chosen to remove or not to remove ovaries and fallopian tubes?

Apart from the medical and physical impacts, removing the ovaries can be emotional for some women. This includes those who have completed childbearing.

Women may experience both positive and negative emotions either after removal of their ovaries or if they choose to keep their ovaries[15, 32].

The possible emotional impact after removing the ovaries

- Sense of relief and peace of mind
- Feeling incomplete as they have lost part of their female identity
- Emotional distress from the impact on sexual intimacy or other menopausal symptoms

The possible emotional impact of NOT removing the ovaries

- A sense of relief as they can avoid possible side effects of menopause
- Women feeling anxiety towards cancer may constantly feel anxious and worried about developing cancer
- False sense of security of being free from cancer (as normal findings from ovarian screening does not necessarily means being free from cancer)

Discuss with your doctor the need for psychosocial support and how it can help to improve your emotional well-being.

What matters most to you?

We have explored the reasons from Malaysian BRCA carriers who decided to remove or not to remove their ovaries. You can browse the statements listed over at page 55 and reflect on how these apply to you. At the end of Section 3, we hope you are able to choose the option that is right for you.

SECTION 3: WHAT MATTERS MOST TO YOU?

This section is divided into two parts. Please tick (√) how likely each statement is true to you. You may add your reason(s) if they are not listed below.

Part A: My concerns about removing ovaries

	Strongly agree	*Agree*	*Neither agree or disagree*	*Disagree*	*Strongly disagree*	*Not Applicable*
FEELINGS ABOUT MY OVARIAN CANCER RISK						
1. I am worried about getting ovarian cancer (e.g. because of family history, chemotherapy)	☐	☐	☐	☐	☐	☐
2. I want to reduce my cancer risk as much as possible to increase my chance to live longer	☐	☐	☐	☐	☐	☐
MY FEELINGS ABOUT REMOVAL OF THE OVARIES						
3. I feel insecure because screening is not reliable to detect ovarian cancer early	☐	☐	☐	☐	☐	☐
4. I prefer to follow my doctor's advice because the doctor always knows what is best	☐	☐	☐	☐	☐	☐
5. Removing unaffected ovaries does not conflict my religious belief	☐	☐	☐	☐	☐	☐
6. I feel confident removing my ovaries as the surgery is simple	☐	☐	☐	☐	☐	☐
THINKING ABOUT MY ROLE AS A WOMEN/WIFE/MOTHER						
7. I have no concern to remove my ovaries (i.e. I am menopausal, completed childbearing)	☐	☐	☐	☐	☐	☐
8. My worry about getting cancer is greater than my worry about the side effects of menopause	☐	☐	☐	☐	☐	☐
9. I am willing to manage the menopause side effects with my doctor	☐	☐	☐	☐	☐	☐
10. I want to live longer for my loved ones (i.e. to be there for my children)	☐	☐	☐	☐	☐	☐
11. My husband/family support me to remove ovaries	☐	☐	☐	☐	☐	☐

MY OTHER CONCERNS (please add)

_____

_____

_____

REMOVE OVARIES

If you agreed to most of the statements in the part A above (on the left), your leaning is most likely towards removing ovaries.

Part B: My concerns about NOT removing ovaries

	Not Applicable	*Strongly disagree*	*Disagree*	*Neither agree or disagree*	*Agree*	*Strongly agree*
FEELINGS ABOUT MY OVARIAN CANCER RISK						
12. I don't feel that my risk of ovarian cancer is high	☐	☐	☐	☐	☐	☐
13. I believe that my chance to not develop cancer is higher than my chance of developing it	☐	☐	☐	☐	☐	☐
MY FEELINGS ABOUT REMOVAL OF THE OVARIES						
14. Removing ovaries does not guarantee that I will be free from cancer	☐	☐	☐	☐	☐	☐
15. I prefer to remove ovaries only when I have the disease	☐	☐	☐	☐	☐	☐
16. I am concerned that removing unaffected ovaries is not permissible by my religion	☐	☐	☐	☐	☐	☐
17. I am worried about the surgery risks (e.g.surgery complication) and physical function after ovaries removal	☐	☐	☐	☐	☐	☐
THINKING ABOUT MY ROLE AS A WOMEN/WIFE/MOTHER						
18. I am worried about the possibility of long-term side effects of early menopause (e.g. bone thinning, effect on the heart and memory)	☐	☐	☐	☐	☐	☐
19. I am not confident that I can manage the side effects of menopause	☐	☐	☐	☐	☐	☐
20. I may feel incomplete or lose confidence as a woman with my ovaries removed	☐	☐	☐	☐	☐	☐
21. I am worried that removal of my ovaries will affect my relationship with my husband/family (e.g. sexuality, mood swing, opposite opinion about ovaries removal)	☐	☐	☐	☐	☐	☐
22. My husband/family did not give support to remove ovaries	☐	☐	☐	☐	☐	☐

MY OTHER CONCERNS (please add)

_____

_____

If you agreed to most of the statements in the part B above (on the right), your leaning is most likely towards NOT removing ovaries.

NOT REMOVE OVARIES

Decision support and coping options

Some women need decision support from their husband and/or family members. They may need to gain consent or to reach a consensus about removing their ovaries. Other women prefer more detailed information including experience from other carriers and views of their religion on aspects of cancer prevention before making a final decision.

You may skip this part and proceed to Section 5 (last section) if you feel this part is irrelevant or does not apply in your case.

You can tick (√) if the statements below are true for you.

	YES	NO
Do you understand the advantages and disadvantages of each option?	☐	☐
Are you clear about which advantages and disadvantages matter most to you?	☐	☐
Do you have enough support and advice to make a choice?	☐	☐
Do you feel sure about the best choice for you?	☐	☐

SECTION 4: DO YOU NEED SUPPORT?

SECTION 4: DO YOU NEED FURTHER SUPPORT TO HELP YOU MAKE YOUR CHOICE?

Considering the opinions of 'important others'

Many women involve important others when deciding about removing their ovaries.

For some women, reaching a consensus with important others can be challenging because what matters most to them may not be similar to their husband/family members (.E.g.: concern related to menopausal side-effects, different perception about cancer risk, acceptance about removal of unaffected ovaries)

For some women, reaching a consensus with important others can be challenging

You can list down in the table provided on the next page what you believe would be their reasons for choosing certain options to discuss with your doctor.

If possible, ask them to accompany you during your consultation at the clinic to obtain better clarification from the doctor.

SECTION 4: DO YOU NEED SUPPORT?

	Their opinion about the removal of ovaries *(please √)*		Their main concern
HUSBAND/FAMILY	Support me to remove (or NOT remove) my ovaries	☐	
	Does not support me to remove (or NOT remove) my ovaries	☐	
	Undecided	☐	
	Does not provide any support	☐	

You are not alone in facing this difficult decision

Getting to know how other Malaysian BRCA gene carriers decided

You are not alone in facing this difficult decision. We have talked to other women who are carriers in Malaysia. Please see on the right some of things they said. These views may be helpful for you in order to make this important decision.

You can ask your doctor if it is possible to meet with other BRCA carriers around your age who are willing to share their experience about:

- ovaries removal and experience with menopause, or
- ovarian cancer (symptoms, treatment, surgery, and recovery)

WOMEN WHO CHOSE *TO* REMOVE OVARIES

CONCERN ABOUT SEXUALITY

I told my husband that this may affect my sexuality. He said never mind as long as it can save my life. Because our kids are still very young

Married, age 48

CONCERN ABOUT CHEMOTHERAPY

I don't want to go through another chemo. I don't want to see myself dying. Better to go through the hot flushes, don't go through the cancer

Married, age 68

PERSPECTIVE ABOUT OVARY REMOVAL AND FEMININITY

Without ovaries does not necessarily means you are not a woman anymore, because it does not define you as a woman. Just because you don't have ovaries it does not make you any less of a woman

Unmarried, age 38

WOMEN WHO CHOSE *NOT TO* REMOVE OVARIES

RELIANCE ON FAITH

God knows what is good or bad for me. Whatever He gives, I will take it. That's why I always pray that if I meant to get cancer, let it be later on, and just help me in that. That is the reason why I have com e to this decision to keep my ovaries

Married, age 39

CONCERN ABOUT SUDDEN MENOPAUSE

I think, it will be easier if I already show sign of getting into menopausal. The decision would be much easier since you already know you're going there, right? But... but you know I'm still getting my period very regularly

Married, age 45

CONCERN ABOUT SURGERY RISK

I don't want to go through surgery again. I have gone through surgery so many times. Now I have become forgetful, I think because of the anesthetic side effects. So, I don't really…if I can avoid (the surgery) I avoid

Married, age 54

Understanding risk-reducing surgery from a religious point of view

Religious faith is important for most Malaysians. Below are some relevant considerations for Catholic and Muslim persons regarding risk-reducing surgery (removing organ that is disease-free but at-risk of developing cancer).

Buddhism, Christianity, and Hinduism are also important as they may also have their own beliefs about removing unaffected ovaries. However, to date, there is a limited information available regarding the views of these religion about risk-reducing surgery.

If necessary, discuss with your doctor to whom you could be referred to, to gain more detail insights on risk-reducing surgery from your religion's perspective.

a) Catholic view

One review study concluded that surgery for cancer prevention does *"not violate Catholic moral principles"* due to legitimate medical reason.

Even though there is no specific risk management option has been endorsed, it was concluded that this type of surgery is not forbidden[45].

b) Islamic view

Generally, the use of genetic testing and disease prevention are permissible in Islam in accordance to al-tibb *al-nabawi* (The Medicine of The Prophet)[46].

From the general principle of *Maqasid Syari'ah* (The Islamic Law), the ovaries removal in high risk women does not conflict with Islamic teaching.

BRCA mutation carriers have an elevated risk of ovarian cancer that can cause harm. Although removing ovaries has possible negative consequences that may result in other harms (e.g. menopausal side-effects), one may follow this principle:

"When removing harm will result in another harm, a balance must be sought to achieve the lesser degree of the two harms".[47]

From an Islamic principle governing medicine, "the basic concept in useful matters is permissiveness"[49]. This is in line with the principle "preventing harm is preferable to procuring benefits" (*Dar' Al Mafasid Muqaddam 'Ala Jalb Al Manfaah*)[46, 47]

From the general principle of *Maqasid Syari'ah* (The Islamic Law), the ovaries removal in high-risk women does not conflict with Islamic teaching

Seeking for more information

If you need further reading, below are the list of websites developed by non-profit organisations that provide reliable information using lay language.

TOPIC	SUGGESTED WEBSITES
Risk management for BRCA carriers	FORCE: Facing Our Risk of Cancer Empowered • *http://www.facingourrisk.org/understanding-brca-and-hboc/information/risk-management/introduction/index.php*
Preparing before and after surgery of ovaries removal	Pink HOPE • *https://pinkhope.org.au/get-support/resources/for-high-risk-women/* Breastcancer.org • *https://www.breastcancer.org/treatment/surgery/prophylactic_ovary/what_to_expect*
Management of menopausal symptoms	The Malaysian Menopause Society • *http://menopause.org.my/wordpress/* The Obstetrical and Gynaecological Society of Malaysia (OGSM) Menopause Website • *http://www.menopausefacts.org/* Breastcancer.org • *http://www.breastcancer.org/tips/menopausal*
Quality of life after removing ovaries	FORCE: Facing Our Risk of Cancer Empowered • *https://www.facingourrisk.org/understanding-brca-and-hboc/webinars/2013-08-28-body-image-and-sexuality-after-surgery.php*

SECTION 4: DO YOU NEED SUPPORT?

TOPIC	SUGGESTED WEBSITES
Diet and lifestyle	FORCE: Facing Our Risk of Cancer Empowered • *http://www.facingourrisk.org/understanding-brca-and-hboc/information/nutrition-lifestyle/diet-nutrition/basics/diet-and-nutrition.php*
Other available decision aids about risk management of ovarian cancer	Ovarian Cancer: Should I Have My Ovaries Removed to Prevent Ovarian Cancer? • *Developer: Healthwise (United States)* • *https://www.uwhealth.org/health/topic/decisionpoint/ovarian-cancer-should-i-have-my-ovaries-removed-to-prevent-ovarian-cancer/zx3060.html* Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource • *Developer: Fox Chase Cancer Center (Philadelphia, United States)* • *http://www.facingourrisk.org/understanding-brca-and-hboc/publications/newsletter/archives/2006fall/books-ovarian-surgery.php*

SUGGESTED PUBLICATION, BOOKS AND NOVELS	
Stories of BRCA carriers	Can be purchased online e.g. bookdepository.com, amazon.com • *'Waiting for Cancer to Come: Women's Experiences with Genetic Testing and Medical Decision Making for Breast and Ovarian Cancer'* **by Sharlene Hesse-Biber** • *'Designer Genes'* **by Emma Hannigan** • *'Pretty is What Changes: Tough Choices, the Breast Cancer Gene, and Learning How to Live in the DNA Age'* **by Jessica Queller**

THANK YOU FOR USING THIS BOOK AND WE HOPE IT IS HELPFUL IN FACILITATING YOUR DECISION-MAKING PROCESS

SECTION 5: MAKING A CHOICE

If you are ready to make a decision, what decision are you leaning towards?

- ☐ **To remove ovaries**
- ☐ **Not to remove ovaries**
- ☐ **Undecided**

If you are not ready to make a decision at this point, you may discuss your plan with your doctor and the ideal time you want to revisit your options.

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NOTES

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