

OvDex

Oophorectomy Decision Explorer

A decision aid designed to help you
and your doctor make a decision
about risk-reducing ovarian surgery

For women at increased risk of ovarian cancer

OvDex (The Oophorectomy Decision Explorer) has been developed to help you find out more about your options for reducing your ovarian cancer risk. If you are viewing OvDex you should have been referred to it by a doctor or geneticist as you are at increased risk of ovarian cancer.

Please note that OvDex can be personalised by answering three simple questions. You should have seen and answered these questions before viewing these pages, as the information on the following pages has been personalised and is only relevant to women who have a confirmed BRCA1 faulty gene and are 50 years or older

(Information on the following pages relates to the answers indicated in bold writing)

1. Do you have a faulty gene or a family history of Lynch Syndrome?
 - a) Yes, I have a BRCA1 faulty gene**
 - b) Yes, I have a BRCA2 faulty gene
 - c) Yes, I am from a Lynch Syndrome family
 - d) Don't know, I have not been tested for a faulty gene or my genetic test was uninformative
 - e) No, I have been tested and no faulty gene was identified

2. Have you ever had breast cancer?
 - a) No, I have never had breast cancer**
 - b) Yes, I have had breast cancer**

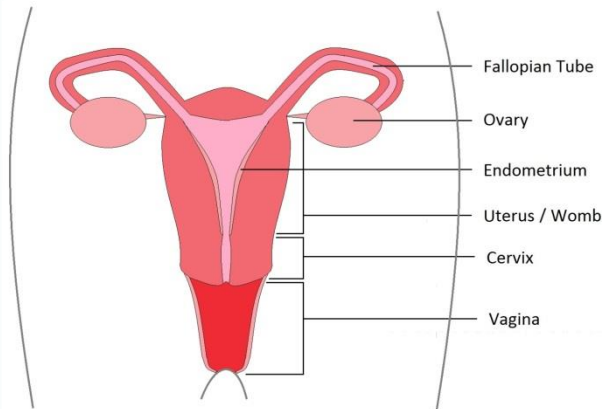
3. How old are you?
 - a) Under 35
 - b) 35-39
 - c) 40-49
 - d) Over 50**

If the answers shown in bold do not apply to you then the information on the following pages may not be relevant to you. Please go back to the website at www.OvDex.co.uk and answer the questions to make the information more relevant to you or to view the general information if you do not wish to personalise OvDex.

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Questions in chapter 1:

- Q1 Where does ovarian cancer develop?
 Q2 What is my ovarian cancer risk with a BRCA1 faulty gene?
 Q3 What is my breast cancer risk with a BRCA1 faulty gene?
 Q4 How will my ovarian cancer risk affect my life?
 Q5 How will my ovarian cancer risk affect my children?
 Q6 How can I change how I feel about my cancer risk?

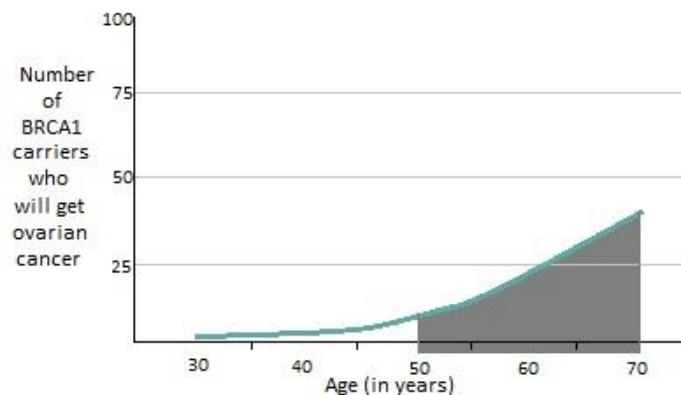
Q1 - Where does ovarian cancer develop?

This picture shows the female reproductive system. The ovaries are connected to the uterus (womb) by the fallopian tubes. Ovarian-type cancer can develop in the ovaries, the fallopian tubes or the lining of the abdomen (called the 'peritoneum'). Other female cancers, such as cancer of the endometrium (the lining of the uterus/womb) or cervix, are very different and should not be confused with ovarian cancer.

For more information about ovarian cancer check out the Cancer Research UK website at www.cancerresearchuk.org and other websites under Contacts & Resources.

Q2 - What is my ovarian cancer risk with a BRCA1 faulty gene?

The risk of developing ovarian cancer for any woman from the general population is about 2 in 100. If you have been found to have a faulty BReast CANCER (BRCA) 1 gene, then your chances of developing ovarian cancer are higher than for the general population.



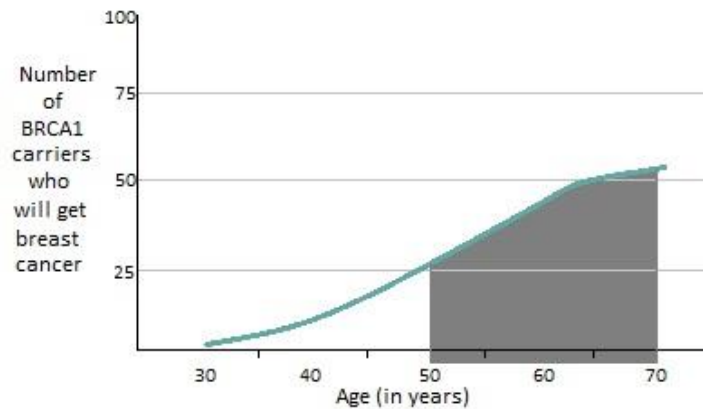
The graph **shows how many out of 100 women with a BRCA1 mutation will develop ovarian cancer** over their life time. By age 70 years about 39 of 100 women with BRCA1 will have developed ovarian cancer. 61 women will not have developed ovarian cancer. Your own age group has been shown with the light grey area. About 15 of 100 people like you develop ovarian cancer by the time they are 60.

Graph created with data produced by Chen et al. (2007)

You said you are over 50 years old, so your risk of developing ovarian cancer is rising and will continue to rise until about 75 years of age.

Q3 - What is my breast cancer risk with a BRCA1 faulty gene?

Because of your BRCA 1 faulty gene you are also at risk of breast cancer.



The graph shows how many out of 100 women with a BRCA1 mutation will develop breast cancer over their life time. By age 70 years about 54 of 100 women with BRCA1 will have developed breast cancer. 46 women will not have developed breast cancer. Your own age group has been shown with the light grey area. About 22 of 100 people like you develop breast cancer by the time they are 60.

Graph created with data produced by Chen et al. (2007)

You said your age at the moment was over 50 years, so your risk of developing breast cancer is rising. Your risk will continue to rise steeply until about 75 years of age.

Q4 - How will my ovarian cancer risk affect my life?

Being at risk for ovarian cancer does not necessarily mean that you will develop ovarian cancer. However, knowing your risk will give you access to additional medical services such as genetic counselling and means that you may be offered risk-reducing surgery. Some people may feel worried or anxious after finding out about their risk and their quality of life may be affected.

Q5 - How will my ovarian cancer risk affect my children?

There is a chance that your children will also have an increased risk of cancer. As you have a faulty BRCA1 gene, your children have a 50/50 chance to inherit this. If a faulty gene has been confirmed in the family, children can choose to get tested for this gene at any time. The best time to get tested should be discussed with your genetic counsellor. If your child/children inherited the faulty gene, then their cancer risk would be the same as yours. If they did not inherit the faulty gene, then their cancer risk would be low. Boys who inherit the faulty gene are not at risk of ovarian cancer, but may be at risk for other cancers. Boys who inherit the faulty gene may also pass it on to their children.

Please also note that cancer risk increases with age and therefore children's risk only starts to rise in later life. More information about genetics can be found on the NHS choices website (see Contacts and Resources).

You can discuss your children's risk with your genetic counsellor to find out more. Your genetic counsellor will also be able to advise you about how best to discuss this risk with your children.

Q6 - How can I change how I feel about my cancer risk?

If you would like to find out more about your risk and what it means, you can use the resources provided in OvDex and talk to your doctor or genetic counsellor.

Knowing that you are at increased risk of cancer might make you feel worried or angry or frustrated. This is completely normal and there is no need to bottle those feelings up. It can actually help to talk about them.

You can try to find someone you trust to talk to or if you prefer to talk to someone you don't know, you can use the contact details for charities and patient support networks under Contacts & Resources. If you have a partner, sharing your thoughts and concerns with your partner can be useful in helping them understand what you are going through and in helping you cope together as a couple.

It may also help to see a positive side to knowing your risk status. For example, this means that you will get access to genetics services and have the chance to do something about your risk. Other women have found it helpful to stay optimistic, have joined patient networks or have found strength in their faith.

Being at risk of cancer may sometimes lead to unwanted thoughts and worry, especially at times when there are no active steps you can take, for example when you are waiting for genetic test results. There are useful techniques you can use to reduce such thoughts. One such method is active distraction, which means actively thinking about something else whenever unwanted thoughts pop in your head. Watch the 'How do I cope' video on the Cancer Genetics Storybank website for a guide of how to do this (see Contacts & Resources).

Relaxation techniques, meditation and guided imagery may also help you deal with any stress you might experience relating to your cancer risk. Examples include progressive muscle relaxation and certain breathing exercises. Visit the 'Mind-body therapy' section on the Macmillan website for more information on and guides to mind-body therapies (see Contacts & Resources).

Questions in chapter 2:

- Q1 What can I do to reduce my risk?
- Q2 Why is there a choice?
- Q3 Who should decide?
- Q4 Who else should I involve in this decision?
- Q5 When should I decide?
- Q6 How can I decide?
- Q7 How can I deal with the choice?

Q1 - What can I do to reduce my risk?

Your doctor has probably discussed with you the option of having risk-reducing ovarian surgery to reduce your ovarian cancer risk. You will need to decide whether and when to have this surgery. Unfortunately, there is no medically proven screening available on the NHS for ovarian cancer at the moment.

This decision aid is designed to help you look at your options. Please refer to chapter 3 (Options at a glance), chapter 4 (Risk-reducing surgery) and chapter 6 (Other options) for more information about surgery, screening and other alternatives.

Q2 - Why is there a choice?

Often when you go to your doctor, there is one clearly recommended treatment. However, some situations are more complicated. These are situations in which your personal preferences and feelings play an important role. In the case of cancer risk reduction, your options have very different effects on your life. This means that you need to be clear about what might happen if you choose one option over the other and how that would impact on your life.

Some health professionals may recommend surgery quite strongly; however you need to make the final decision and before you do, you should consider the possible benefits and risks, how these might affect your life and how you feel about them.

Q3 - Who should decide?

As the best choice for you is based on your preferences, you should be closely involved in the decision. You can either make the decision on your own or if you do not wish to make this decision yourself, your genetic counsellor or gynaecologist can help you. They will encourage you to think about the options and your preferences, so that the final choice is right for you. If you then don't want to choose for yourself, just say so and they may make a recommendation.

Q4 - Who else should I involve in this decision?

Whether or not you would like to bring anyone else into this decision is your choice. Often it is helpful to speak to someone who knows you well, such as a partner, other members of your family or a friend, who could work through this decision with you. If you are in a relationship the views of your partner can be important, especially in the context of risk-reducing ovarian surgery, so it is recommended that you speak to your partner and try to reach a decision together. Your doctor will also be happy for you to bring your partner along to appointments and to answer any questions they might have.

Q5 - When should I decide?

The operation is most effective if it is done at 40 years of age, because ovarian cancer risk starts to rise from age 40 onwards. Additionally, if done at 40, the surgery reduces the risk of breast cancer. However, age 40 may not be ideal for everyone. So, even if you decided not to have it at 40, the operation will still decrease your ovarian cancer risk if performed after that age.

The decision you are facing is not an easy one and you should not feel under any pressure to decide quickly. Risk-reducing surgery has benefits and risks that need to be weighed carefully, so take your time and make sure you are ready before making a decision.

Q6 - How can I decide?

When it comes to important decisions everyone is different. Some people like to find out as much as they can about their options, while others prefer to just know what is absolutely necessary. Some might find it helpful to talk to their family and friends. Some might like to speak to people who have made a similar decision. It really depends on you. Have a think about other important decisions in your life and how you managed to make those. That could give you an idea of how you like to decide about things.

Q7 - How can I deal with the choice?

It can be helpful to create a plan of how and when you will make this choice. If you are not ready to decide right now, it might be useful to set yourself a deadline of when you will revisit this decision. For example: "Just after my 55th birthday I will look at this information again."

Once you are ready you can decide how you want to make this choice:

1. I will decide by myself using everything I have learnt
2. I will decide but seriously consider my doctor's opinion
3. The doctor and I should decide together
4. The doctor should decide but seriously consider my opinion
5. The doctor should decide for me

One constructive way to deal with a difficult decision is to empower yourself with information. OvDex is designed to help you to learn more about ovarian cancer risk and your options. With the wealth of information that is available on the internet, it can be difficult to find reliable and trustworthy information. The information in OvDex is supported by recent scientific findings and has been carefully reviewed by health professionals to make sure it is accurate. You should at least understand your options and their benefits and risks before making a decision. Find out more about the most important questions to ask at: www.Ask3Questions.co.uk. Once you have read the information in OvDex, it could help to make a note of any remaining questions and take those to your doctor or genetic counsellor for a more detailed discussion.

You may feel that you are not comfortable making decisions about your health. This is okay. You do not need to make the choice alone if you don't want to. You can decide together with your doctor or ask them to make the choice for you. But you need to remember that you are the expert when it comes to your own life and that only you know what is important to you. So even if you decide to let the doctor make the decision for you, make sure they know about your goals and values. Tell them what is important to you.

Frequently asked questions	Surgery to remove ovaries and fallopian tubes	No surgery
Will this reduce my risk of ovarian cancer?	Yes, removing the ovaries and fallopian tubes will reduce your lifetime risk of ovarian-type from 39 in 100 to about 2 in 100.	No, your risk of ovarian cancer will remain increased.
Is there a routine screening programme to detect ovarian cancer?	No, there is no evidence that screening for ovarian cancer is effective and after surgery your risk is sufficiently low that, even if screening was available, it would not be necessary.	No, there is no evidence that screening for ovarian cancer is effective in saving lives.
Will this change how I feel about my risk of ovarian?	You may feel less worried about developing ovarian cancer. Most women report feeling satisfied with their decision after surgery.	You may worry about developing ovarian cancer.
Will this change how I feel about myself as a woman?	Many women do not notice any change in how they feel about themselves as a woman. However, your desire for and/or enjoyment of sex is likely to decrease.	Not applicable.
Will I get menopausal symptoms again?	No, if you have completed the menopause removing your ovaries should not cause any menopausal symptoms to recur. If you are peri-menopausal and have not quite completed the menopause some symptoms may occur.	No, everything will remain the same. If you have completed the menopause you should not experience any more menopausal symptoms. If you are peri-menopausal and have not quite completed the menopause some symptoms may occur.
What are the risks of surgery?	About 4 in every 100 patients experience a complication during or after surgery. These can be minor infections or major complications. Discuss this with your clinician.	Not applicable.
How long will it take me to recover from surgery?	Most women leave the hospital the same day or the day after key hole surgery and are back to normal in 4 weeks. For open surgery time in hospital and recovery will be longer. During recovery you may feel pain / tiredness and may need help with everyday tasks.	Not applicable.

Q1 – How can I cope with this decision?

Some women may find it useful to discuss surgery with others, who have already made this decision. In some areas your genetic counsellor may be able to put you in touch with someone who has already gone through the decision, otherwise you can use the contact details for charities and patient support networks under Contacts & Resources to read about or get in touch with others in a similar situation. Going over the decision with someone who knows you well, such as your partner or a member of your family can also help you clarify your decision. If you decide to opt for surgery and you are in a relationship, preparing yourself together with your partner for the time after surgery can help you both deal better with any consequences of the operation.

Being clear about the reasons why surgery could be the right or wrong thing for you can help you make a decision and avoid regretting it later. The information in OvDex is designed to help you identify the benefits and the risks of surgery and any other options, so you can decide for yourself. The exercise called 'Your Decision' can help you clarify what is most important to you.

There may be times when there are no active steps you can take, for example if you have decided to defer surgery or while you are waiting for your surgery appointment. During these times you may sometimes worry about your risk or experience unwanted thoughts. Useful techniques to reduce such worries and thoughts, especially at times when you cannot do anything but wait, include active distraction, relaxation techniques, meditation and guided imagery. Check out the 'How do I cope' video on the Cancer Genetics Storybank website and the Macmillan website for more information on these techniques (see Contacts & Resources).

Questions in chapter 4:

- Q1 What is risk-reducing bilateral salpingo-oophorectomy (RRSO)?
- Q2 What are the main advantages of this operation?
- Q3 What are the main disadvantages of this operation?
- Q4 How much would my risk be reduced by surgery?
- Q5 What is my risk after surgery?
- Q6 What does the surgery involve?
- Q7 How long does it take to recover?
- Q8 Do I need to have my womb removed as well?
- Q9 What are the complications of RRSO?
- Q10 Could cancer be found during the surgery?
- Q11 How would RRSO affect my life?

Q1 - What is risk-reducing bilateral salpingo-oophorectomy (RRSO)?

Risk-reducing bilateral salpingo-oophorectomy (RRSO for short) is an operation to remove healthy ovaries and fallopian tubes to reduce the cancer risk. The word 'salpingo-oophorectomy' means surgical removal of the fallopian tubes (salpinges) and ovaries. The term 'bilateral' in this context describes the fact that the ovaries and fallopian tubes on both sides of the body are removed. The aim of the operation is to remove these tissues before cancer develops.

Q2 - What are the main advantages of this operation?

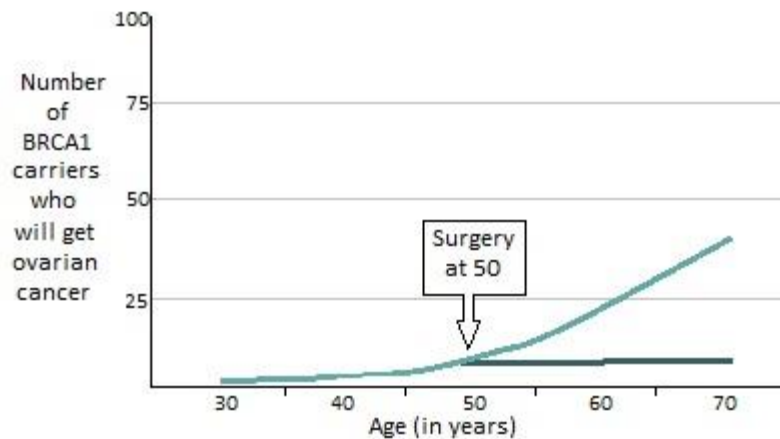
- 1) This operation will reduce your ovarian and fallopian tube cancer risk, as these are completely removed during surgery.
- 2) For some women, not having to worry about ovarian cancer anymore comes as a great relief.
- 3) Having the surgery will also prevent other, non-cancer related problems happening with the ovaries, such as cysts, which can cause some discomfort and pain.

Q3 - What are the main disadvantages of this operation?

- 1) Your desire for sex is likely to decrease.
- 2) There is a small risk of complications during and after surgery.

Q4 – How much would my risk be reduced by surgery?

Your ovarian-type cancer risk would be greatly reduced by surgery. It will fall from a risk of 39 in every 100 women like you to about 2 in every 100 women like you.



The graph shows **how many out of 100 women with a BRCA1 faulty gene will develop ovarian cancer** over their life time and the effect of surgery on this number. By age 70 years about 39 of 100 women with BRCA1 will have developed ovarian cancer (Light line). If women have surgery when they are 50, then the number of women who develop ovarian cancer stops rising (Dark line).

Graph created with data produced by Chen et al. (2007)

Studies have shown that women with a faulty BRCA1 gene profit most from surgery when they have it at 40, so that the risk does not start to rise steeply. However, having surgery later is still useful if you decide d to delay.

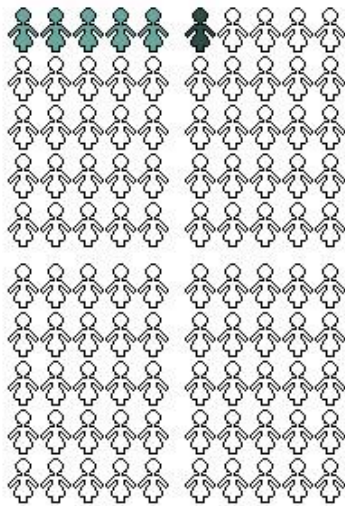
Q5 - What is my risk after surgery?

After surgery your risk of ovarian and fallopian tube cancer is greatly reduced, however, there is a rare type of cancer which may still develop after surgery that is very similar to ovarian cancer. This is called primary peritoneal cancer and develops in the lining of the abdomen and pelvis. Unfortunately, the peritoneum cannot routinely be removed during RRSO. Your primary peritoneal cancer risk after surgery is about 2 in 100, which is similar to the risk of ovarian cancer in the general population.

Q6 - What does the surgery involve?

Most often the operation is done as keyhole surgery (laparoscopy). This involves 3 or 4 small (about 1cm) cuts, usually one cut is close to your belly button and 2-3 just below the bikini line, so they are not visible. Keyhole surgery itself usually takes less than 2 hours.

In some cases it may not be possible to do keyhole surgery, because of previous surgery on your tummy or because of your weight. Then surgeons use the more traditional open surgery. This means a longer cut, usually along the bikini line. Sometimes a surgeon might have to convert to an open operation when doing keyhole surgery because of complications or old scar tissue. This happens in about 1 of every 100 keyhole operations.



Type of procedure in 100 women who have the operation

The figure on the left shows **how many of 100 women will have keyhole surgery, open surgery** and planned keyhole which is converted to open surgery.

94 of 100 women will have planned keyhole surgery (white figures). Five of 100 women will have planned open surgery (light teal figures). One of 100 women will have planned keyhole surgery which is converted to open surgery (dark figure).

Q7 - How long does it take to recover?

75 of 100 patients who have keyhole surgery leave the hospital the day after surgery. They are usually back to normal activity about 4 weeks after surgery. If you have open surgery you are likely to stay in hospital a bit longer. Usually patients leave the hospital about 5 days after open surgery and are back to normal in about 6 weeks. After surgery you are not allowed to do any heavy lifting for a few weeks. You may also have to refrain from driving until you can comfortably wear a seatbelt and make an emergency stop without pain.

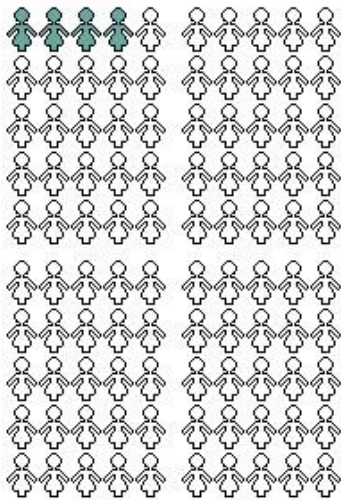
Q8 - Do I need to have my womb removed as well?

No, normally it is not necessary that you have your womb removed at the same time as having RRSO, unless you have other problems with your womb and have been told by a doctor that removing the womb would help you with those problems. You should discuss this with your doctor.

Q9 - What are the complications of RRSO?

There is a small risk of complications linked to RRSO. About 4 in every 100 people will experience some complication. Minor complications can include wound or urinary tract infections and usually have no long-term effects on your health. More serious complications might happen during surgery and can include damage to blood vessels, the bowel or the bladder. If you are having keyhole surgery this might mean that the surgeon has to convert to open surgery to repair the damage. There are a number of other rare complications that might happen and your surgeon will go through those with you if you wish before you go in for surgery.

Please note that about 96 of every 100 women do not experience any complications at all.



Complications in 100 women who have the operation
The figure on the left shows **how many of 100 women will experience complications** during or after surgery. 4 of 100 women will experience some kind of complication either during or after surgery. 96 of 100 women will not experience any complications.

As with any surgery, there is a very small risk of death. However, this is highly unlikely. The risk may be greater in women with health problems before surgery.

Q10 - Could cancer be found during the surgery?

Yes, although this is rare. Once your ovaries and fallopian tubes have been removed they will be checked thoroughly for any signs of cancer. There is a chance that cancer may be discovered during this check. This happens in up to 4 out of every 100 operations in women with a BRCA faulty gene.

If cancer is found during the surgery, you will be informed as soon as possible and might have to undergo further tests, treatment and surveillance.

Q11 - How would RRSO affect my life?

In the short-term, if you decide to go for surgery, you will have to take time off work and will not be able to do some of the things you might usually do, such as driving or heavy lifting. Therefore you may need help with everyday tasks. During recovery you may also feel some pain and discomfort and you may be more tired than usual. However most women recover fully within 4 to 6 weeks.

In the longer term there are a number of things you should consider. After surgery you may feel less worried about ovarian cancer. However you may feel differently about your body and you may lose interest in sex. These factors may affect your life after surgery and should be considered carefully before making a decision.

Questions in chapter 5:

Q1 What is surgical menopause?

Q2 Will I go into surgical menopause even if I am already menopausal?

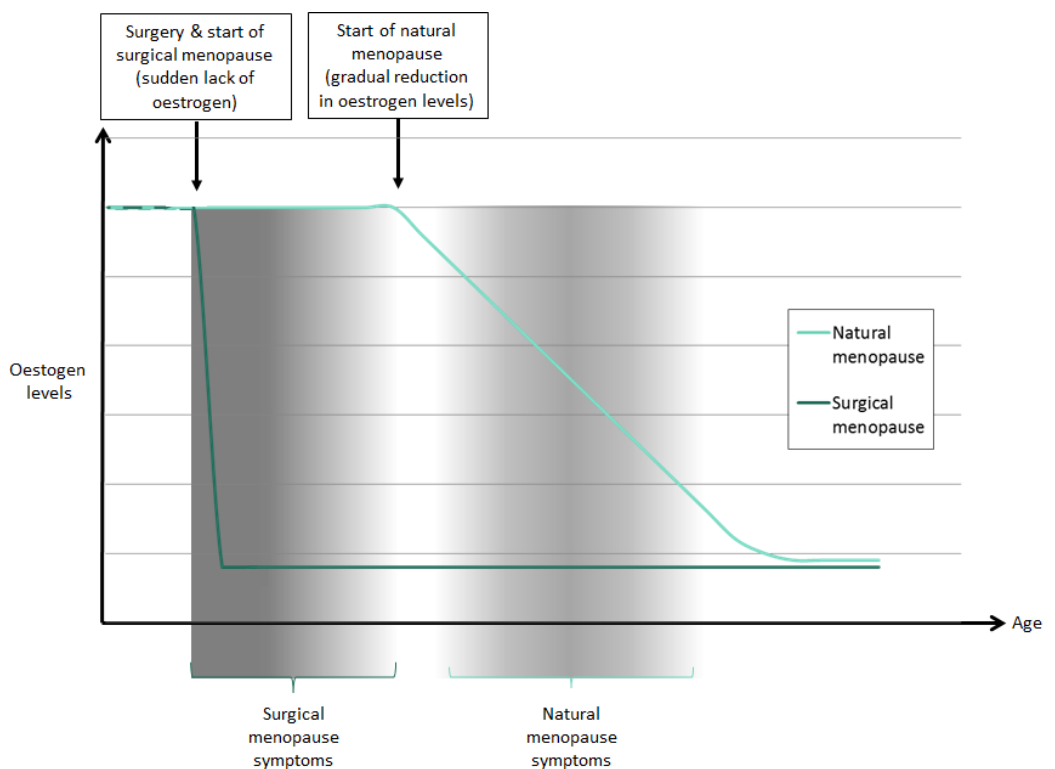
Q3 Is there anything I can do to reduce the effects of the menopause?

Q4 Will I go into surgical menopause even if I have already gone through the menopause?

Q1 - What is surgical menopause?

A surgical menopause is a menopause you enter when your ovaries are removed by surgery and your body no longer produces the female hormone oestrogen. A surgical menopause is essentially the same as a natural menopause, it only happens earlier and more suddenly. Therefore a surgical menopause results in the same symptoms as a natural menopause. These symptoms are caused by the lack of oestrogen. As oestrogen levels drop suddenly after surgery, the symptoms of a surgical menopause start instantly and can be more severe than those of a natural menopause, in which oestrogen levels fall gradually.

However, if you have already started the menopause, your oestrogen levels have already begun to fall and therefore the drop in levels after surgery is less extreme.



The graph above shows the drop in the levels of the female hormone oestrogen during surgical and natural menopause. Potential menopausal symptom duration and severity are indicated in shades of grey.

Q2 - Will I go into surgical menopause even if I am already menopausal? It

Yes, even if you are already menopausal and experiencing some of the symptoms of the natural menopause you will go into surgical menopause after surgery. However, as your oestrogen levels have already started to fall due to the natural menopause, the symptoms of the surgical menopause you will experience will not be as severe as those experienced by women in their 30s, whose oestrogen levels were still high before surgery.

Common menopausal symptoms you may experience are: Hot flushes, night sweats, mood swings, vaginal dryness and loss of interest in sex. Other symptoms include difficulty sleeping, fatigue, weight gain, changes in memory and depression.

Q3 - Is there anything I can do to reduce the effects of the menopause?

Yes. There are several options available to help you deal with the short-term symptoms of surgical menopause. These include physical options, such as lubricant to counteract vaginal dryness, or psychological options, such as sex counselling and cognitive behavioural therapy to improve emotional and physical functioning. You can get more information about these options from your genetics services.

You can also take dietary supplements, however before doing so you should speak to your doctor. An active lifestyle and healthy diet have also been shown to improve well being after surgery.

It is not recommended that women over the age of 50 take hormone replacement, therefore this option is not mentioned further here.

Q4 – Will I go into surgical menopause even if I have already gone through the menopause?

No, if you have already fully completed the menopause before having the surgery, then your ovaries have already stopped working and your oestrogen levels have fallen. Therefore you will not experience symptoms of the surgical menopause and you will not have to go through the menopause again.

Questions in chapter 7:

Q1 Is there any screening available for ovarian cancer?

Q2 Are there any other options apart from surgery?

Q3 But I have been offered CA125 blood tests and/or trans-vaginal scans?

Q4 What would happen if I do not have surgery?

Q5 Is there anything else I can do?

Q1 - Is there any screening available for ovarian cancer?

No. Unfortunately there is no medically proven screening available for ovarian cancer.

Two large trials of ovarian cancer screening were done recently. But the results are not yet available, so we do not yet know whether this screening is effective and can detect ovarian cancer early. The UKFOCS trial offered high risk women CA125 blood tests every four months and one yearly trans-vaginal ultrasound scan. The UKCTOCS trial offered such screening to women over 50, who were not at high risk. Both trials have not reported their final outcomes. Routine screening will not be offered until the results of these trials are available and only if these trials show that screening is effective and can save lives. This website will be updated as soon as the results are available.

Some areas or GPs may offer private, self-funded CA125 and/or trans-vaginal screening to high risk women, however women need to be aware that there is still no proof that this screening is effective in detecting ovarian cancer early. Therefore going to private screening may provide false reassurance. Additionally, screening may result in unnecessary worry and anxiety if any results show changes that turn out not to be cancer.

You should also be aware that the yearly smear test you receive is designed to detect cervical cancer and will not detect ovarian cancer.

Any woman with symptoms of ovarian cancer is likely to be offered a diagnostic CA125 test and trans-vaginal ultrasound scan. Please note that these diagnostic tests are not screening tests. Rather, they are designed to detect ovarian cancer when symptoms have already developed. Women with no symptoms will not be offered routine screening on the NHS until the screening has been shown to be effective.

Q2 - Are there any other options apart from surgery?

At the moment the official alternative to surgery is to do nothing and simply be aware of the symptoms of ovarian cancer should they develop. However it is important to realise that these symptoms can be very vague and are not specific to ovarian cancer. If any of these symptoms happen more than 12 times a month you should contact your GP.

The symptoms of ovarian cancer include:
Persistent bloating (big or swollen tummy)
Feeling less hungry or feeling full quickly
Persistent pain in your tummy or below
Needing to urinate more than usual

Often these symptoms are similar to symptoms of other diseases, such as Irritable Bowel Syndrome and might be easily confused. Therefore it is very important that you tell your GP that you have a family history of cancer.

Q3 – But I have been offered CA125 blood tests and/or trans-vaginal scans?

Some centres and/or GPs may offer private CA125 tests or trans-vaginal scans to women at high risk of ovarian cancer. As these are not offered as screening tests by the NHS you may have to pay for these yourself. You can choose to have these tests done, but you should be aware that there is no evidence that these screening tests are effective at detecting ovarian cancer early. Therefore using such screening services might provide you with false reassurance.

Q4 - What would happen if I do not have surgery?

If you decide not to have surgery, then nothing will really change. You will need to look out for any symptoms and if you think anything is wrong you need to go to your GP to get it checked. You know your body best, so don't be afraid to go to your GP if you notice anything unusual. Make sure you tell your GP that you have a family history of ovarian cancer and are at increased risk of ovarian cancer when you talk to them.

Remember you can reconsider surgery at any time. If screening for ovarian cancer is shown to be effective in the future, you may then be offered screening as an alternative to surgery.

Q5 - Is there anything else I can do?

As there is no routine screening available, you can choose to have screening privately, but you should be aware that this has not yet been shown to be effective. You should also keep an eye on any symptoms.

Studies have found that a healthy diet with plenty of fruit and vegetables, keeping a healthy weight and an active lifestyle can improve overall well-being and might reduce your chances of getting cancer.

In the exercise on the next few pages you can rate some facts depending on how much they make you want **to have** or want **to avoid** surgery. Give each fact a ranking number (e.g. from 1 (a little) to 3 (a lot), then add the numbers up to see where you stand.

The table below is already filled in to give you an example. On page 21 you will find an empty table for you to fill in.

The fact that...	Makes me want to have surgery	Does not come into my decision	Makes me want to avoid surgery
...surgery will reduce my ovarian cancer risk	3		
...there is no effective screening for ovarian cancer, so I cannot get checked out regularly	2		
...the symptoms of ovarian cancer are very vague, so I may not notice them early	1		
...I might feel different about my body after surgery			3
...I might enjoy sex less after surgery		X	
...there is a risk of complications linked to surgery			1
Enter your own reasons:			
Have to take time off work			1
Add together the numbers in each column:	6		5

Below you can enter the overall number into the scales. Then note down how you feel about the decision and where you stand.

The scales below are already filled in to give you an example. On page 22 you will find an empty scale for you to fill in.



More weight for than against surgery:

Overall your answers show that at this moment in time you are leaning towards having the surgery. Even though you may have some reasons why you would want to avoid surgery, they are not as important to you as the reasons that make you want surgery. Therefore you could now make an appointment to discuss this decision with your doctor and go through any concerns you might have.

Same weights both sides:

Overall your answers show that at this moment you are completely undecided about whether or not to have surgery. Your reasons for why you would want to have and why you would want to avoid surgery balance each other out. Therefore you may want to discuss your options further with your doctor/genetic counsellor.

More weight against than for surgery:

Overall your answers show that at this moment in time you are leaning towards not having surgery. Even though you may have some reasons why you would want to have surgery, they are not as important to you as the reasons that make you want to avoid surgery. Therefore at this moment in time surgery is probably not the right option. However, keep in mind that things may change over time and that eventually you may lean more towards surgery. You can come back to OvDex and do this exercise again anytime to see whether anything has changed.

Overall decision: My reasons for surgery weigh more than those
against surgery, but I am still not sure. The
numbers are very similar.

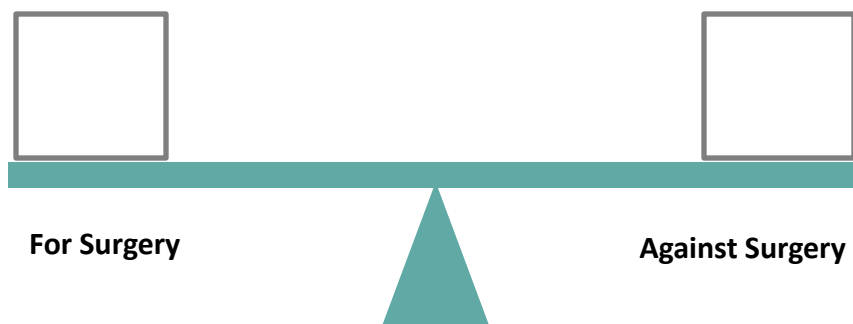
My action plan: I will make an appointment with my gynaecologist
to talk about the risk of surgery in my case.
Will talk to my boss about taking time off and
whether it would cause any problems.

In the exercise on the next few pages you can rate some facts depending on how much they make you want **to have** or want **to avoid** surgery. Give each fact a ranking number (e.g. from 1 (a little) to 3 (a lot), then add the numbers up to see where you stand.

Make sure you give the score on the correct side of the table.

The fact that...	Makes me want to have surgery	Does not come into my decision	Makes me want to avoid surgery
...surgery will reduce my ovarian cancer risk			
...there is no effective screening for ovarian cancer, so I cannot get checked out regularly			
...the symptoms of ovarian cancer are very vague, so I may not notice them early			
...I might feel different about my body after surgery			
...I might enjoy sex less after surgery			
...there is a risk of complications linked to surgery			
Enter your own reasons:			
Add together the numbers in each column:			

Below you can enter the overall number into the scales. Then note down how you feel about the decision and where you stand.



More weight for than against surgery:

Overall your answers show that at this moment in time you are leaning towards having the surgery. Even though you may have some reasons why you would want to avoid surgery, they are not as important to you as the reasons that make you want surgery. Therefore you could now make an appointment to discuss this decision with your doctor and go through any concerns you might have.

Same weights both sides:

Overall your answers show that at this moment you are completely undecided about whether or not to have surgery. Your reasons for why you would want to have and why you would want to avoid surgery balance each other out. Therefore you may want to discuss your options further with your doctor/genetic counsellor.

More weight against than for surgery:

Overall your answers show that at this moment in time you are leaning towards not having surgery. Even though you may have some reasons why you would want to have surgery, they are not as important to you as the reasons that make you want to avoid surgery. Therefore at this moment in time surgery is probably not the right option. However, keep in mind that things may change over time and that eventually you may lean more towards surgery. You can come back to OvDex and do this exercise again anytime to see whether anything has changed.

Overall decision: _____

Q1 – How can I take my decision forward and how can I cope?

If you are considering surgery, the next step is to make an appointment with a health professional. This can be your GP, genetic counsellor or gynaecologic surgeon. With them, you can discuss surgery further and get answers to any additional questions, before booking an appointment with a hospital. You can also seek a second professional opinion at any time if you wish.

Preparing yourself for having surgery, both mentally and physically, can help to cope with the operation and with recovery time. It can also help to think about the support you do have and how different people might be able to help you. This can include simple things such as driving you to and from the hospital, helping you out with household chores or childcare issues right after surgery.

If you decide not to have surgery it might be helpful to speak to your GP and let them know about your risk. Some women also find it reassuring to have an action plan in case they feel like any symptoms develop. This can be a simple reminder, such as a plan to contact your doctor if symptoms last 2 weeks or longer.

My action plan:

Here are some links and contact details that you might find helpful (even though we have taken great care in choosing websites from reliable sources please note we are not responsible for the content of these websites):

The Cancer Genetics Story Bank – An online collection of stories told by patients and professionals about cancer genetics, genetic testing and risk-reduction decisions. Developed by the Cancer Genetics Service for Wales (CGSW)

www.cancergeneticsstorybank.co.uk

NHS Choices – A website created by the NHS to provide information to patients. Includes information on ovarian cancer, genetics and genetic testing.

www.nhs.uk

Tenovus – A Welsh cancer charity for anyone affected by cancer. Tenovus provides information about cancer via a website, as well as practical and emotional support through the support-line.

www.tenovus.org.uk or call the support line on 0808808 1010

Macmillan – A UK charity for anyone affected by cancer with good information about genetic testing for cancer and mind-body therapies

www.macmillan.org.uk or call the support line on 0808 808 00 00

Target Ovarian Cancer – A UK charity which supports research into ovarian cancer and provides useful information including an 'Ask the Expert' feature. Available in several languages.

www.targetovariancancer.org.uk

Ovacom – A UK charity providing information and support for everyone affected by ovarian cancer. Includes links to a number of patient blogs.

www.ovacom.org.uk or call the supportline on 08453710554

FORCE (Facing Our Risk of Cancer Empowered) – A US based charity providing support, education, advocacy and information on research specific to hereditary cancer focusing on living with and managing ovarian (and breast) cancer risk.

www.facingourrisk.org

The BRCA Umbrella – A network for carriers of BRCA mutations with numerous blogs and patient stories and opportunities to network with others via social media.

www.brcaumbrella.ning.com

Your GP and/or Genetics Service – There to help you with any questions or concerns.

Evidence for cancer risk

Cancer Research UK (2011) Cancer Stats: Ovarian Cancer – UK. Available as pdf from CancerResearchUK.org [Accesses July 2012]

Chen S and Parmigiani (2007) Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 25(11): 1329–1333

Mavaddat N, Peock S, Frost D, Ellis S, Platte R, Fineberg E, et al.; EMBRACE (2013) Cancer risks for BRCA1 and BRCA2 mutation carriers: results from prospective analysis of EMBRACE. *J Natl Cancer Inst* 105(11):812-22

Evidence for cancer risk after surgery

Finch A, Beiner M, Lubinski J, Lynch HT, Moller P, Rosen B, et al.; Hereditary Ovarian Cancer Clinical Study Group (2006) Salpingo-oophorectomy and the risk of ovarian, fallopian tube, and peritoneal cancers in women with a BRCA1 or BRCA2 Mutation. *JAMA*. 296(2):185-92

Finch A, Lubinski J, Moller P, Singer CF, Karlan B, Senter L, Rosen B, Maehle L, Ghadirian P, Cybulski C, Huzarski T, Eisen A, Foulkes WD, Kim-Sing C, Ainsworth P, Tung N, Lynch HT, Neuhausen S, Metcalfe KA, Thompson I, Murphy J, Sun P and Narod SA (2014) Impact of Oophorectomy on Cancer Incidence and Mortality in Women With a BRCA1 or BRCA2 Mutation. *Journal of Clinical Oncology*. ePub before print, doi: 10.1200/JCO.2013.53.2820

Evans DG, Clayton R, Donnai P, Shenton A, Lalloo F. (2009) Risk-reducing surgery for ovarian cancer: outcomes in 300 surgeries suggest a low peritoneal primary risk. *Eur J Hum Genet*. 17(11):1381-5

Rebbeck TR, Kauff ND, Domchek SM. (2009) Meta-analysis of risk reduction estimates associated with risk-reducing salpingo-oophorectomy in BRCA1 or BRCA2 mutation carriers. *J Natl Cancer Inst*. 101(2):80-7

Domchek SM, Friebel TM, Singer CF, Evans DG, Lynch HT, Isaacs C, Garber JE, Neuhausen SL, Matloff E, Eeles R, Pichert G, Van t'veer L, Tung N, Weitzel JN, Couch FJ, Rubinstein WS, Ganz PA, Daly MB, Olopade OI, Tomlinson G, Schildkraut J, Blum JL, Rebbeck TR. (2010) Association of Risk-Reducing Surgery in BRCA1 or BRCA2 Mutation Carriers With Cancer Risk and Mortality. *JAMA*. 1;304(9):967-75

Evidence for surgical procedure and complication rate

Kenkhuis MJ, de Bock GH, Elferink PO, Arts HJ, Oosterwijk JC, Jansen L, Mourits MJ. (2010) Short-term surgical outcome and safety of risk reducing salpingo-oophorectomy in BRCA1/2 mutation carriers. *Maturitas*. 2010 Jul;66(3):310-4

Manchanda R, Abdelraheim A, Johnson M, Rosenthal AN, Benjamin E, Brunell C, Burnell M, Side L, Gessler S, Saridogan E, Oram D, Jacobs I, Menon U. (2011) Outcome of risk-reducing salpingo-oophorectomy in BRCA carriers and women of unknown mutation status. *BJOG*. 2011 Jun;118(7):814-24

Rieck GC, Lim K, Rogers, MT, France E, Grey JR, Amso N, Howells RH, Fiander AN (2006) Screening for familial ovarian cancer – management and outcome of women with moderate to high risk of developing ovarian cancer. *Int Gynecol Cancer*. 16 Suppl.1:86-91

Evidence for menopause and symptoms

Finch A, Metcalfe KA, Chiang JK, Elit L, McLaughlin J, Springate C, Demsky R, Murphy J, Rosen B, Narod SA. (2011) The impact of prophylactic salpingo-oophorectomy on menopausal symptoms and sexual function in women who carry a BRCA mutation. *Gynecol Oncol*. 121(1):163-8

Evidence for other options

Rosenthal A, Jacobs I. (2006) Familial ovarian cancer screening. *Best Pract Res Clin Obstet Gynaecol* 20(2):321–38.

Rosenthal AN, Fraser L, Manchanda R, Badman P, Philpott S, Mozersky J, Hadwin R, Cafferty FH, Benjamin E, Singh N, Evans DG, Eccles DM, Skates SJ, Mackay J, Menon U, Jacobs IJ. (2012) Results of Annual Screening in Phase I of the United Kingdom Familial Ovarian Cancer Screening Study Highlight the Need for Strict Adherence to Screening Schedule. *J Clin Oncol*. [Epub ahead of print] doi: 10.1200/JCO.2011.39.7638

Rosenthal AN, Fraser L, Philpott S, Manchanda R, Badman P, Hadwin R, Evans DG, Eccles D, Skates SJ, Mackay J, Menon U, Jacobs I (2013) Final results of 4-monthly screening in the UK Familial Ovarian Cancer Screening Study (UKFOCSS Phase 2). *Journal of Clinical oncology* 31(15,Suppl.):Abstract No 5507

Kushi LH, Doyle C, McCullough M, Rock CL, Demark-Wahnefried W, Bandera EV, Gapstur S, Patel AV, Andrews K, Ted Gansler T and The American Cancer Society 2010 Nutrition and Physical Activity Guidelines Advisory Committee (2012) American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention reducing the Risk of Cancer With Healthy Food Choices and Physical Activity. *CA:A Cancer Journal for Clinicians* 62 (1):30–67

National Institute for Clinical Excellence (2011) Ovarian cancer: the recognition and initial management of ovarian cancer; Guidance document CG122; National Collaborating Centre for Cancer, available at: NICE.org.uk [Accessed December 2011]

NHS Choices (2012) Ovarian cancer symptoms. Available from NHS.uk [Accessed October 2012]

National Institute for Health and Clinical Excellence (2013) CG164 Familial breast cancer. Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer. NICE guideline [accessed July 2013] (available at: www.nice.org.uk/nicemedia/live/14188/64202/64202.pdf).

Evidence for coping advice

Schwartz MD, Lerman C, Miller SM, Daly M, Masny A. (1995) Coping disposition, perceived risk, and psychological distress among women at increased risk of ovarian cancer. *Health Psychol.* 14(3):232-5.

Thirlaway K, Fallowfield L, Nunnerley H, Powles T. (1996) Anxiety in women 'at risk' of developing breast cancer. *Br J Cancer.* 73(11):1422-4.

Park CL, Folkman S (1997) Meaning in the context of stress and coping. *Review of General Psychology*, 1(2):115-144.

Appleton S, Garcia-Minaur S, Porteous M, Campbell J, Anderson E, Watson M, Cull A. (2003) Development of a psycho-educational intervention for women living with an increased risk of breast cancer. *Patient Educ Couns.* 55(1):99-104.

Appleton S, Watson M, Rush R, Garcia-Minaur S, Porteous M, Campbell J, Anderson E, Cull A (2004) A randomised controlled trial of a psycho-educational intervention for women at increased risk of breast cancer. *Br J Cancer.* 90(1):41-7.

Phelps C, Bennett P, Iredale R, Anstey S, Gray J. (2006) The development of a distraction-based coping intervention for women waiting for genetic risk information: a phase 1 qualitative study. *Psychooncology.* 15(2):169-73

Vilela LD, Nicolau B, Mahmud S, Edgar L, Hier M, Black M, Franco EL, Allison PJ. (2006) Comparison of Psychosocial Outcomes in Head and Neck Cancer Patients receiving a Coping Strategies Intervention and Control Subjects Receiving no Intervention. *J Otolaryngol.* 35(2):88-96.

Bennett P, Phelps C, Brain K, Hood K, Gray J. (2007) A randomized controlled trial of a brief self-help coping intervention designed to reduce distress when awaiting genetic risk information. *J Psychosom Res.* 63(1):59-64.

Manne SL (2007) Coping with Cancer: Findings of research and intervention studies. In Martz E, Livneh H and Wright BA (Eds) *Coping with Chronic Illness and Disability* (2007), pp 191-213; Springer ISBN: 978-0-387-48668-0

Beatty LJ, Koczwara B, Rice J and Wade TD (2010) A randomised controlled trial to evaluate the effects of a self-help workbook intervention on distress, coping and quality of life after breast cancer diagnosis. *Med J Aust* 193(5):68.

Beatty LJ, Koczwara B and Wade TD (2011) 'Cancer Coping Online': A pilot trial of a self-guided CBT internet intervention for cancer-related distress. *E-Journal of Applied Psychology – Clinical and Social Issues* 7(2)

Phelps C, Bennett P, Hood K, Brain K, Murray A. (2012) A self-help coping intervention can reduce anxiety and avoidant health behaviours whilst waiting for cancer genetic risk information: Results of a Phase III randomised trial. *Psychooncology.* doi: 10.1002/pon.3072. [Epub ahead of print]

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