

# OvDex

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## 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 this document as the information on the following pages has been personalised and is only relevant to women who have had a negative genetic test result (no faulty gene was identified).

(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 unclear
  - 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**

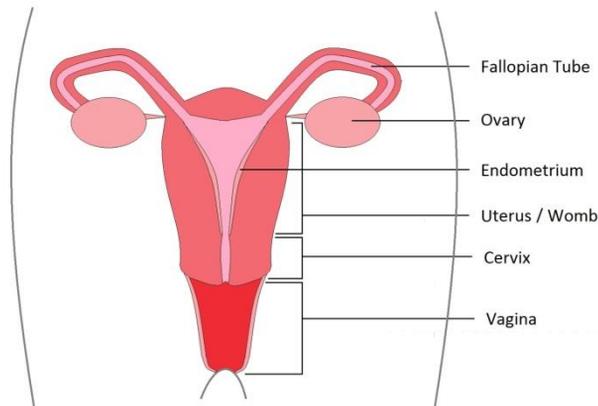
If the answers shown in bold do not apply to you then the information on the following pages may not be relevant to you. Please go back to the website at [www.OvDex.co.uk](http://www.OvDex.co.uk) and answer the questions to make the information more relevant to you or to view the general information 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 if no faulty gene was found?

**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](http://www.cancerresearchuk.org) and other websites under Contacts & Resources.

**Q2 - What is the ovarian cancer risk if no faulty gene was found?**

If no faulty gene was found your genetic test is said to be 'negative' and there are two possibilities:

1. Someone else in your family has already been tested and has been found to have the faulty gene. Now you have been found not to have this gene.

In this case your risk of ovarian cancer is likely to be low.

2. You were the first person to be tested in your family and were not found to have a faulty gene.

In this case your risk of ovarian cancer may still be higher than the general population, as science is not yet able to find all the faulty genes that might be linked to ovarian cancer. You should discuss this with your genetic counsellor.

**Questions in chapter 2:**

As you have not been found to carry a faulty gene, there are different situations that might apply to you. Please find the situation below that applies to you.

1. What if my genetic test is negative and I am from a family where a faulty gene has been found before?
2. What if my genetic test is negative and I am the first person to be tested?

**1. What if my genetic test is negative and I am from a family where a faulty gene has been found before?**

In this case your risk of ovarian cancer is likely to be low, therefore you do not need to make a decision about risk-reducing surgery at this point.

**2. What if my genetic test is negative and I am the first person to be tested?**

As your risk of ovarian cancer may be high even though your test was negative, you may still need to decide about whether or not to have risk-reducing surgery. You can come back to this decision aid once you have found out more about your risk from your genetic counsellor. You can also go back to the main page of the OvDex website and have a look at the general information if you wish to find out more about surgery.

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](http://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](http://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](http://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](http://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](http://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](http://www.ovacom.org.uk) or call the supportline on 08453710554

**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]

Domchek SM, Gaudet MM, Stopfer JE, Fleischaut MH, Powers J, Kauff N, Offit K, Nathanson KL, Robson M. (2010) Breast cancer risks in individuals testing negative for a known family mutation in BRCA1 or BRCA2. *Breast Cancer Res Treat*, Vol. 119(2):409-14.

Kauff ND, Mitra N, Robson ME, Hurley KE, Chuai S, Goldfrank D, Wadsworth E, Lee J, Cigler T, Borgen PI, Norton L, Barakat RR and Offit K (2005) Risk of Ovarian Cancer in BRCA1 and BRCA2 Mutation-Negative Hereditary Breast Cancer Families. *Journal of the National Cancer Institute*, Vol. 97(18):1382-1384

Järvinen HJ, Renkonen-Sinisalo L, Aktán-Collán K, Peltomäki P, Aaltonen LA, Mecklin JP. (2009) Ten years after mutation testing for Lynch syndrome: cancer incidence and outcome in mutation-positive and mutation-negative family members. *J Clin Oncol.*, Vol. 27(28):4793-7.

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