

## Fact sheet 9

### Screening for ovarian cancer

We, Ovacome, are a support network for people affected by ovarian cancer in the UK. We provide information and support, raise awareness and put you in touch with others who are suffering from ovarian cancer.

#### What is screening?

Screening is testing to check that you are not in the early stages of a disease, before you experience any symptoms.

In the UK there are currently screening programmes for breast, cervix and bowel cancer. Before the NHS makes a screening test available, the test has to be proven to be accurate and safe. There are ongoing studies to find a screening test for ovarian cancer.

#### Why might screening for ovarian cancer be important?

The early stage of ovarian cancer (stage 1 – cancer in one or both ovaries) can be successfully treated. Unfortunately, most ovarian cancers are not found at this early stage for a number of reasons.

First, ovarian cancer appears more commonly after the menopause (when your periods have stopped). The ovaries are not active at this time, so if they behave abnormally, it is not easy to notice. Second, the ovaries are deep in the pelvis and are difficult to examine. Finally, even when you have symptoms, they are usually vague and not specific. These symptoms could be due to a number of other causes.

For these reasons, by the time most women with ovarian cancer develop symptoms and their cancer is found, it has spread outside

the ovaries to the pelvis (stage 2), the abdomen (stage 3) or the lungs and liver (stage 4). This makes it far more difficult to treat successfully.

This information suggests that an effective method of screening to find ovarian cancer at an early stage may save the lives of many women who develop the cancer.

#### What screening tests are available?

There are three possible ways of screening for ovarian cancer.

##### 1 Internal examination

An internal examination can be performed to detect enlarged ovaries. Although an internal examination can detect large ovarian tumours, even experienced doctors are not able to reliably detect ovarian cancer at an early stage.

This means that an internal examination is not an effective method for detecting early ovarian cancer.

##### 2 The CA125 blood test

CA125 is a protein released into the blood, and is at a high level in most women with ovarian cancer. The CA125 test is often used to check for ovarian cancer in women who have symptoms. It is also used to check women during and after treatment for ovarian cancer.

A high level of CA125 can also be due to a number of other reasons, such as pregnancy, menstruation, fibroids and endometriosis.

The CA125 test is a quick blood test, which is sent to the laboratory.

### **3 Ultrasound**

Ultrasound scanning is the same technique as is used in pregnancy, and can be used to look at the size and texture of the ovaries. In ovarian cancer, the ovaries get bigger and the texture becomes abnormal due to growths.

Some of these abnormal features are also found in ovarian tumours and other conditions in the pelvis that are not cancer. As with the CA125 test, ultrasound results can be abnormal, even when there is no cancer.

Ultrasound scans can be performed either by placing an ultrasound probe on your tummy or by putting a probe into your vagina. This is called a trans-vaginal scan and usually gives a clearer picture.

### **How effective are screening tests?**

Screening can detect ovarian cancer early. Some large studies have looked at using either CA125 or ultrasound to screen for ovarian cancer. Two of the largest studies of screening for ovarian cancer have been performed in the UK.

The King's College Study looked at ultrasound as a way of screening, in over 5000 women. The results showed that ultrasound can detect cases of ovarian cancer at an early stage.

The Royal London and St Bartholomew's Hospital Study looked at using both CA125 and ultrasound as a way of screening, in 22,000 women. The results showed that it was possible to detect many cases of ovarian cancer before symptoms developed.

It is uncertain whether screening actually saves lives from ovarian cancer. Although screening with CA125 and ultrasound, either separately or together can detect ovarian cancer early, this does not necessarily mean that screening will save lives. Screening will only be worthwhile if it detects ovarian cancer early enough to make treatment more effective.

Large studies are in progress (see below) and until they have reported their findings, it is unclear whether screening can save lives or not.

### **What are the problems with screening for ovarian cancer?**

The main problem with screening for ovarian cancer is that the CA125 test and ultrasound scans can be abnormal in women who do not have ovarian cancer. These sorts of results called 'false positives' could cause you a great deal of anxiety.

You might need an operation to rule out the possibility of ovarian cancer. Operations can have serious complications. If no cancer is found, then the operation was unnecessary.

As ovarian cancer is relatively uncommon, it works out that more abnormal screening results are due to false-positive findings rather than cancer.

Most women find a normal screening result reassuring. However, the CA125 test or ultrasound scan will not pick up every case of ovarian cancer. These sorts of results called 'false negatives' do happen, and this means a small number of women will be wrongly reassured that they do not have cancer.

## What studies are in progress?

### UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS)

A very large study of ovarian cancer screening has been set up in the UK. This study called UKCTOCS (UK Collaborative Trial of Ovarian Cancer Screening) involves 200,000 women aged 50 to 74 years.

UKCTOCS is a randomised trial, which means that women who agree to take part are randomly chosen for screening with CA125, screening with ultrasound, or to be part of a control group who are followed up without screening. This random selection is important to get really clear answers about how effective screening for ovarian cancer is at saving lives.

The study will eventually provide information about the number of lives which can be saved by screening, the cost of screening, the psychological effect of screening and the problems caused by false-positive results. These results should be available in 2014.

Recently this study reported some early findings which are encouraging. These suggested that screening might be detecting a higher number of ovarian cancers at earlier stages than you might expect, and that screening might be detecting cancers many months before they have caused symptoms. However, these early results do not prove that screening will save lives. This means it is important that we wait for the final results of the study before making any decisions about whether screening can achieve this result.

UKCTOCS is being run by the Gynaecological Cancer Research Centre at University College London and is funded by the Medical Research Council, Cancer Research UK and the National Health Service. You can find details of the trial at [www.ukctocs.org.uk](http://www.ukctocs.org.uk).

The Eve Appeal is the only UK charity dedicated to funding research in all four gynaecological cancers. You can get more information at [www.eveappeal.org.uk](http://www.eveappeal.org.uk) or by phoning 020 7380 6900.

### The UK Familial Ovarian Cancer Screening Study (UKFOCCS)

This is a national study to assess and improve screening in women with a strong family history of ovarian cancer. A strong family history means that two or more close relatives have had ovarian cancer, or one relative has had ovarian cancer and another has had breast cancer that happened at a young age (under 50). If you think you fall into this group, you can ask your GP for advice.

You may be referred to a specialist genetics centre to confirm your family history. Most genetics centres will know how to enrol you, if appropriate, into this screening study. The study involves a CA125 blood test every four months and a yearly ultrasound scan. The study is due to stop taking on new volunteers at the end of 2009, and results are expected in 2012.

## What should I do about ovarian cancer screening?

You may be worried about your risk of developing ovarian cancer, particularly if you have a relative or friend who has had ovarian cancer. It is understandable that if you have experience of ovarian cancer, you may want to be screened.

There is no absolute right or wrong advice about screening, but it is important to be aware of the limits and disadvantages to the current ways of screening. Broad guidelines are provided below, but an experience with ovarian cancer may influence your decision.

### Women under 50 with no family history

If you are under 50 and have no family history of ovarian cancer or breast cancer, your risk of ovarian cancer is small. The risk of a false-positive screening result is high. Screening is not recommended if you fall into this group.

## **Women over 50 with no family history**

There is no evidence that screening is of value to women in this age group, and there are disadvantages associated with screening. For this reason, routine screening is not recommended. However, if you fall into this group you may have been invited to take part in one of the ongoing screening trials for the general population.

## **Women with a weak family history**

Many women in this group will have one close relative who has developed ovarian cancer and will be understandably anxious about their own risk. If you fall into this group, your risk is slightly but not greatly increased and the value of screening is uncertain. Some centres do offer advice and counselling to women with a weak family history.

With a weak family history, you would have been eligible for the UKCTOCS trial. However, this trial has now finished taking on people and screening in the UK outside this trial is not currently recommended.

## **Women with a strong family history**

If you have a strong family history you may be at a significantly increased risk of ovarian cancer, and you may want to take part in the UK Familial Ovarian Cancer Screening Study (UKFOCSS). You should have access to a specialist centre for expert advice about preventing ovarian cancer as well as screening. You may then be offered a place in the UKFOCSS.

Screening for women at high risk of ovarian cancer does not have any proven benefits. Many women at a high risk decide to have their ovaries removed to prevent the disease developing. You will be told about this option after meeting with a geneticist who can accurately assess your risk.

## **Where can I get advice about screening and my risk of ovarian cancer?**

If you think you may be at high risk, you can ask your GP to refer you to a specialist genetics clinic.

The Familial Ovarian Cancer Clinic at University College London Hospitals NHS Trust is a genetics clinic and aims to give you advice about your personal risk of ovarian cancer. After taking a detailed family and medical history, you are given an assessment of your risk of ovarian and other cancers. You will get advice about screening methods, genetic testing and ways to prevent getting the cancer.

The clinic can arrange surgery to remove your ovaries if you are at high risk, but you must first have appropriate counselling. The clinic is an NHS service available to women referred by their GP who want advice about their risk of ovarian cancer.

The Macmillan website at [www.macmillan.org.uk](http://www.macmillan.org.uk) has an interactive software program called OPERA (Online Personal Education and Risk Assessment) for genetic breast and ovarian cancer. If you know your family medical history, OPERA can give you personalised information and advice on whether you might have inherited the genetic risk of breast and ovarian cancer. It offers you advice about where to go for more information and support.

If you would like more information or you would like to discuss anything to do with ovarian cancer, phone our support line on 0845 371 0554, Monday to Friday from 9am to 4pm. Or, you can visit our website at [www.ovacome.org.uk](http://www.ovacome.org.uk).

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