

Information for Women with High Risk or Familial Histories of Ovarian Cancer

Patient Information

Introduction

This leaflet has been written for women who have a known high risk of developing ovarian cancer at some stage in their life. We hope it will answer some of the questions that you or those close to you may have. It is not meant to replace the discussion between you and your doctor but helps you to understand more about what is discussed.

What are the ovaries?

The ovaries are two small oval-shaped organs which are part of the female reproductive system. They are in the lower part of the abdomen, which is known as the pelvis.

Each month, in women of childbearing age, one of the ovaries produces an egg. The egg passes down the fallopian tube to the womb (uterus). If the egg is not fertilised by a sperm it passes out of the womb and is shed, along with the lining of the womb, as part of the monthly period. The ovaries also produce the female sex hormones, oestrogen and progesterone. As a woman nears the 'change' (menopause) the ovaries make less of these hormones and periods gradually stop.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, the division and growth of cells is orderly and controlled but if this process gets out of control for some reason, the cells will continue to divide and develop into a lump which is called a tumour. Tumours can either be benign or malignant. Cancer is the name given to a malignant tumour.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

Why do I have a high risk of developing ovarian cancer?

Although ovarian cancer is generally a rare disease, some types appear more often in some families. This may be because of a

genetic issue that causes faulty biological information to be passed down through families.

The majority of women who develop ovarian cancer have few symptoms until the cancer has spread. By then the cancer is more difficult to treat. However treatment is often successful in women diagnosed before the ovarian cancer has spread.

What is screening?

Carrying out certain tests on a regular basis may help detect ovarian cancer at an early stage. This is called screening. Current screening tests have been shown to detect ovarian cancer before symptoms occur but at present it is not known whether screening can save lives.

Screening involves looking for certain things on a regular basis to detect cancer at an early stage. We know that detecting cancer early gives most people a better chance of being treated successfully. Screening is not foolproof and will not prevent ovarian cancer. You will receive an appointment for screening every five years.

The screening programme involves having an ultrasound scan and a blood test, called a CA 125, each year.

What is an ultrasound scan?

An ultrasound scan is very safe and uses sound waves rather than X-rays to create a picture of the inside of your body. There are two different ways of performing a scan. The first way looks through the wall of the abdomen (similar to the way a baby in the womb is scanned). This is known as transabdominal scanning. The second way is to insert a thin probe into the vagina. This is known as transvaginal scanning. This method of scanning gives a much clearer picture of the ovaries and should be no more uncomfortable than having a smear test. If, however, transvaginal scanning is not possible or acceptable a transabdominal scan will be performed. Ultrasound tests can show other types of abnormality in the ovaries, for example ovarian cysts that often occur naturally in women still having periods. If these are large the ultrasound will be repeated in a few weeks to check that they have disappeared.

If the ultrasound finds any changes which are suspicious you will be referred to a specialist for further investigations.

What is a CA 125 blood test?

The blood test is to measure a substance called CA 125 in the blood. This is released at higher levels into the blood in most but not all women with ovarian cancer. CA 125 is sometimes known as a 'tumour marker' because finding it suggests that a specific kind of tumour may be in the body.

CA 125 blood tests can sometimes be high for reasons other than cancer. If you were found to have a high CA 125, the test would be repeated and, if necessary, further investigations can be arranged. Not all ovarian tumours make CA 125 and it is possible that ovarian cancer could develop without it being detectable in the blood.

What are the risks of screening?

There is no guarantee that all early ovarian cancers will be picked up by screening, and should you develop any symptoms that you are concerned about, you should see your doctor as soon as possible.

For some women, screening itself can lead to further anxiety. It also increases the risk of false alarms. As a result women who are screened have a higher chance of undergoing unnecessary surgery, with all the associated risks.

Are other options available?

We are aware that this screening strategy has not yet been proved to be fully effective. One of the other options is to have an operation to remove the ovaries and try and prevent ovarian cancer developing.

Removing the ovaries can often be done with keyhole surgery although in some cases it is necessary to do open surgery. If successful, keyhole surgery leaves three or four scars. Removing the ovaries does not give 100% protection against developing ovarian cancer, but it does reduce the risk very considerably. It also reduces the risk of breast cancer because removing your ovaries reduces the levels of oestrogen in your body.

Some breast cancers need oestrogen to develop and lowering the amount in your body can prevent these cancers developing or cause them to grow more slowly.

Are there any risks or complications?

As with any operation and general anaesthetic there are risks but it is important to know that most women do not have serious complications.

You will also become menopausal. This means that your fertility will end. You may also experience symptoms such as hot flushes, dry skin, and dryness of the vagina, feeling low and anxious and being less interested in sex for a time. Many of these symptoms can be eased by hormone replacement therapy (HRT).

If you are considering having surgery to remove your ovaries, you will be given more information about the risks and benefits of surgery.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow-up clinic appointments. If you have any questions at all, please ask your surgeon, oncologist or nurse. It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatients appointments.

Glossary of medical terms used in this information:

Fallopian tube: one of a pair of long, slender tubes that transport eggs released from the ovary to the womb.

Menopause: the time at which menstruation ceases and your fertility ends. Also known as 'the change'.

Oestrogen: the female sex hormone, produced by the ovaries.

Ovaries: one of two small oval bodies in which eggs and hormones are developed.

Transabdominal scan: a scan performed by passing sound waves

through the abdomen.

Transvaginal scan: a scan performed by passing sound waves through the vagina.

Tumour marker: a substance found in the bloodstream which indicates the presence of a specific type of tumour.

Ultrasound scan: ultrasound examination uses high frequency sound waves, which are transmitted through the skin. This is used to form a picture of the inside of your abdomen (tummy). Gel is placed on your abdomen and a small hand-held scanner moved across your skin. This is a painless procedure which transmits pictures onto a television screen. The examination takes about 10 to 15 minutes. Detailed instructions will be sent with your appointment letter.

Local sources of further information

You can visit any of the health/cancer information centres listed below:

Birmingham Women's NHS Foundation Trust

Health Information Centre
Birmingham Women's Healthcare NHS Foundation Trust
Metchley Park Road
Edgbaston
Birmingham B15 2TG
Telephone: 0121 627 2608

Heart of England NHS Foundation Trust

Health Information Centre
Birmingham Heartlands Hospital
Bordesley Green
Birmingham B9 5SS
Telephone: 0121 424 2280

Cancer Information and Support Centre
Good Hope Hospital
Rectory Road
Sutton Coldfield B75 7RR
Telephone: 0121 424 9486

Sandwell and West Birmingham Hospitals NHS Trust

The Courtyard Centre
Sandwell General Hospital (Main Reception)
Lyndon
West Bromwich B71 4HJ
Telephone: 0121 507 3792
Fax: 0121 507 3816

University Hospital Birmingham NHS Foundation Trust

The Patrick Room
Cancer Centre
Queen Elizabeth Hospital
Edgbaston
Birmingham B15 2TH
Telephone: 0121 697 8417

Walsall Primary Care Trust

Cancer Information & Support Services
Challenge Building
Hatherton Street
Walsall WS1 1YB
Freephone: 0800 783 9050

About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge and practice at the time of publication.

We are constantly striving to improve the quality of our information. If you have a suggestion about how this information can be improved, please contact us via our website:

<http://www.birminghamcancer.nhs.uk>.

This information was produced by Pan Birmingham Cancer Network and was written by Consultant Surgeons, Clinical Nurse Specialists, Allied Health Professionals, Patients and Carers from the following Trusts:

Heart of England NHS Foundation Trust
Sandwell and West Birmingham NHS Trust
University Hospital Birmingham Foundation Trust
Walsall Hospital NHS Trust
Birmingham Women's Hospital Foundation Trust

We acknowledge the support of Macmillan in producing this information.

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Publication Date: May 2010

Review Date: May 2013