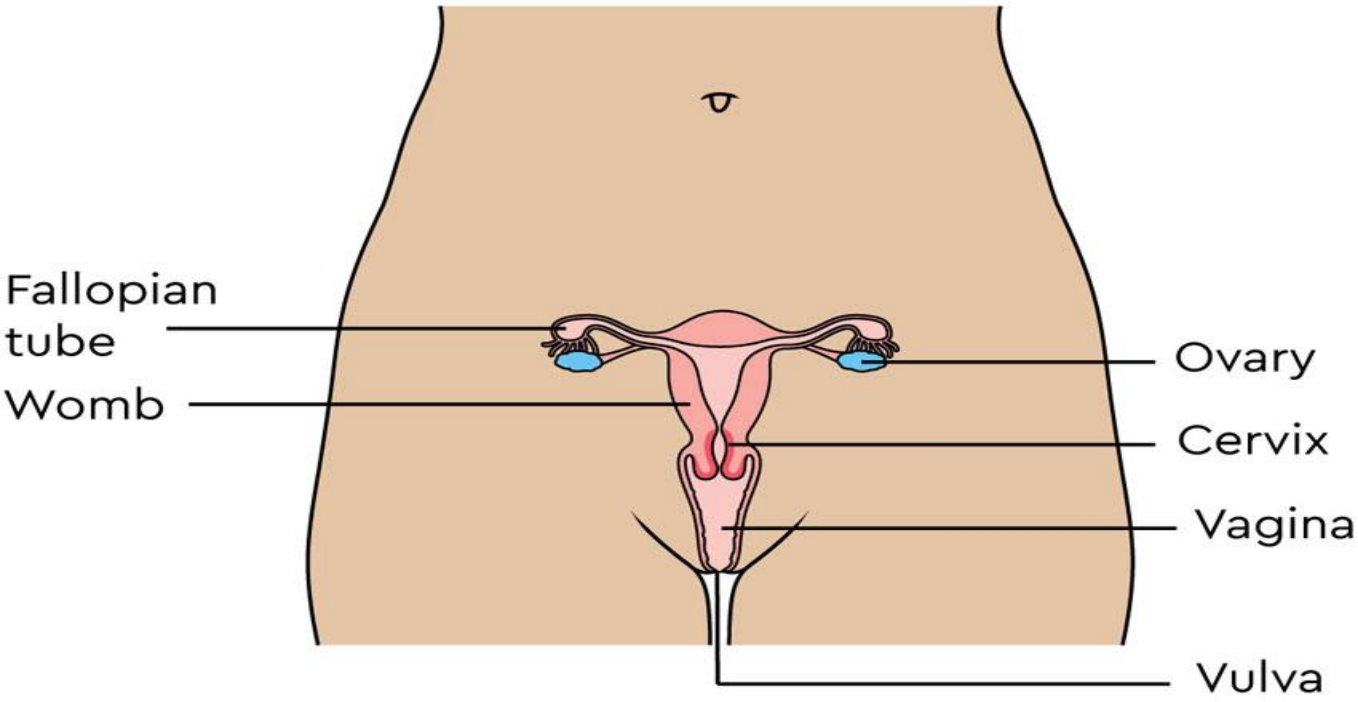
Cancer services

Ovarian germ cell cancer

Information for patients, relatives and carers

Introduction

This booklet is designed to give you information about your treatment for ovarian germ cell cancer. Ovarian germ cell cancer is different from ovarian cancer. We hope these pages will answer some of the questions that you or those who care for you may have. This booklet is not meant to replace the discussion between you and your medical team. It aims to help you understand more about what is discussed.



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The ovaries

The ovaries are two small oval-shaped organs, which are part of the female reproductive system. The ovaries are about the size and shape of an almond and sit just above the fallopian tubes. There is one ovary on each side of the womb (uterus). Each month, in women of childbearing age, an egg leaves one of the ovaries and makes it way down to the womb. If the egg is not fertilised, it breaks down and is shed, along with the lining of the womb, as part of the monthly period or menstruation. Ovaries also produce the female sex hormones oestrogen and progesterone.

Germ cells and germ cell tumours of the ovary

Germ cells are the cells in the body that develop into sperm and eggs. In women, they are mainly found in the ovary. However, they can sometimes be left behind in other parts of the body from when you developed in your mother's womb. Germ cell tumours arise from these cells.

The most common germ cell tumour is testicular cancer in men, but women can also develop germ cell tumours in the ovary. Ovarian germ cell tumours are very rare and account for only about one or two per cent of cancers of the ovary. Most ovarian germ cell tumours occur in teenagers or young women, although they may rarely occur in women in their 60s.

Doctors usually remove germ cell cancers with surgery, and this may be all the treatment you need. However, you will sometimes be offered chemotherapy after surgery to reduce the chances of the cancer coming back. Germ cell tumours generally respond very well to chemotherapy and most people are cured.

Germ cell cancers that have spread can still be successfully treated and cured with chemotherapy. Your consultant will discuss these risks with you.

Different types of germ cell tumours

Germ cell tumours are not all the same. They vary in the way they look under a microscope and in the way they behave. It is important for your doctors to know which kind of germ cell tumour you have so they can give you the most effective treatment. The different kinds of germ cell tumours are described below.

Dermoid cyst or mature teratoma

A dermoid cyst is benign (non-cancerous) and is known as a mature teratoma. Very occasionally, a dermoid cyst can become malignant (cancerous).

Dysgerminomas

This is a malignant form of germ cell tumour. It is the female equivalent of testicular seminoma. It is much more common in adolescence and early adult life.

Non-dysgerminomatous germ cell tumours

These are a malignant group of very rare tumours. There are many technical names for this family of tumours including choriocarcinoma, yolk sac tumour and embryonal carcinoma. Again, these tumours are more common in girls or young women.

Causes

The causes of germ cell tumours are unknown. Germ cells are a normal part of the ovary, but sometimes changes in these cells make them divide and grow too quickly, resulting in the formation of a tumour.

Signs and symptoms

Ovarian germ cell tumours can be hard to diagnose early. The most common symptoms include:

- abdominal pain
- a feeling of fullness or abdominal swelling
- sometimes an increasing need to pass urine

Some women may have irregular vaginal bleeding.

How germ cell tumours are diagnosed

When ovarian germ cell cancer was first suspected you will have had a series of blood and imaging tests at your local hospital. If appropriate, your local hospital may have removed the affected ovary and fallopian tube (this procedure is called a unilateral salpingo-oophorectomy).

This is done during an operation known as a laparotomy, where a cut is made into the abdominal wall to allow the surgeon to remove the ovary. Once the ovary has been removed, it is sent for examination under a microscope. The doctor can then tell whether it is a germ cell tumour and if so, what type it is

A combination of these early tests and a laparotomy gives valuable information about the size and location of your germ cell tumour. This process is called ‘staging’.

Staging of germ cell tumours

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site. Knowing the particular type and the stage of the cancer helps the doctors decide on the best treatment for you.

Germ cell cancer of the ovary, like ovarian cancers, is staged using the International Federation of Gynaecology and Obstetrics (FIGO) system.

The FIGO system gives a number between 1 and 4 to the cancer, depending on how widespread the cancer has become.

For example:

- stage 1 cancer means that one or both ovaries are affected by the cancer
- stage 4 usually means that the cancer has spread to other organs outside the abdominal cavity

A letter (a, b or c) can also sometimes be added after the number to give more detail about how the tumour has spread.

Referral to Charing Cross hospital

You have been referred to Charing Cross hospital for specialist treatment or a second opinion. The team will discuss your individual circumstances with you.

Blood tests

You will have a blood test to see whether or not chemicals called tumour markers are being released into the bloodstream.

A tumour marker is a substance found in the blood when a cancer is present. These are useful in the diagnosis and treatment of certain types of germ cell tumour, although not all ovarian germ cell tumours produce these tumour markers.

The main markers produced by germ cell tumours are: alpha-fetaprotein (AFP), human chorionic gonadotrophin (HCG), cancer antigen 125 (CA125), lactate dehydrogenase (LDH).

Treatment for germ cell tumours

Ovarian germ cell is successfully treated in the majority of cases. The treatment you have will depend on the site and type of germ cell tumour. Treatment will usually involve a combination of surgery and chemotherapy. Your consultant will discuss the treatment options with you.

Imaging tests

You will often have fresh imaging tests performed when we see you at Charing Cross Hospital. These may include a CT scan of the chest and abdomen, MRI scan of the head and pelvis all with contrast. We may also do an ultrasound of the pelvis. If you have had these tests done before in the past month in your local centre, we may not need to do them again. Your clinical team will discuss this with you.

Surgery

The initial treatment for germ cell tumours is usually the removal of the affected ovary and fallopian tube (called unilateral salpingo-oophorectomy). This is done during an operation known as a laparotomy, where a cut is made into the abdominal wall to allow the surgeon to remove the ovary.

In most cases, it is only necessary to remove the affected ovary and the fallopian tube. This will not affect your ability to have children. However, sometimes it may be necessary to remove both ovaries, both fallopian tubes, and the womb (called a total abdominal hysterectomy and bilateral salpingo-oophorectomy).

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by disrupting the growth of cancer cells.

The drugs are usually given as injections or via a drip (infusion) into a vein in your arm (intravenously). Often a combination of chemotherapy drugs is given. Sometimes it is not necessary to follow the surgery with chemotherapy if the tumour is found at a very early stage. Sometimes chemotherapy is given before any surgery to shrink a tumour and make it easier to operate on. This is called neo-adjuvant chemotherapy.

If chemotherapy is necessary, it will require a hospital stay for several nights each cycle. Your individual treatment plan will be discussed with you.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays that destroy cancer cells, while doing as little harm as possible to normal cells. It is very occasionally used to treat particular types of germ cell tumours of the ovary.

What happens after treatment?

After treatment your team will monitor you closely. This monitoring will involve:

- Blood tests
- Medical examination
- x-rays
- Scans

What you need will depend on:

- How your cancer first looked under the microscope (the original histology)
- The treatment you had
- Your initial response to the treatment

You will need these tests for several years. If you have any problems, or notice any new symptoms such as abdominal pain, abdominal swelling or an increased need to pass urine please let your clinical team know as soon as possible.

Fertility

We take your fertility into account when deciding:

- initial surgery to treat ovarian germ cell cancer can affect your fertility as you may have had one or both ovaries removed and perhaps had a hysterectomy.
- most women who receive treatment for ovarian germ cell cancer can go on to conceive a pregnancy normally
- if you have had one ovary removed, your other ovary should still produce eggs
- if both ovaries have been removed you will need egg donation and in-vitro fertilisation (IVF) to get pregnant
- it is only if you have had a hysterectomy – although this is more unusual – that you will not be able to carry a pregnancy

If your consultant decides you need chemotherapy and you are worried about your fertility or want to consider egg preservation, please discuss this with the clinical team.

Your feelings

Everyone has their own way of coping with difficult situations. Some people find it helpful to talk to family or friends, while others prefer to seek help from people outside their situation. Some people prefer to keep their feelings to themselves. There is no right or wrong way to cope, but help is available if you need it. Please talk to your team about the help available.

Who is my specialist nurse?

Your clinical nurse specialist (CNS) is a nurse who is specially trained to give you individualised care and support. At least one of them will have introduced themselves to you during your visit. You can contact them via the Macmillan cancer navigator service – see the details below.

Further sources of support and information

Macmillan cancer navigator service at Imperial College Healthcare NHS Trust

This is a single point of contact for cancer patients at Imperial College Healthcare NHS Trust, and their family, friends and carers. The service is here to help you to navigate your care and resolve queries that you may have. Our Navigators can access information about your appointments, connect you to appropriate services and signpost you on to further support. They can also book you in for a telephone call back from your clinical nurse specialist (CNS) if you have a question that needs clinical input.

The service is open Monday to Friday 08:30 to 16.30 excluding bank holidays. (The service is closed for training between 14.00- 14.45 on Thursdays.)

Call: 020 3313 0303

Macmillan cancer information and support service at Imperial College Healthcare NHS Trust

The Macmillan cancer information and support service offers free support and information to anyone affected by cancer, including family and loved ones. The service has physical centres at Charing Cross and Hammersmith Hospitals, and also offers virtual and telephone support.

When you call or visit you can speak to one of the Macmillan cancer team one-on-one about whatever matters most to you. You can sign up to a range of weekly virtual groups that provide the opportunity to connect with other people with cancer in a relaxed environment. You can also speak to our Macmillan welfare and benefits adviser, who can offer patients of the Trust tailored advice on additional financial support.

The service is open Monday-Thursday (excluding bank holidays), with various drop-ins available within our physical centres. For more information please call us on 020 3313 5170 or email **imperial.macmillansupportservice@nhs.net**

Maggie's West London

Maggie's is a cancer charity that provides the emotional, practical and social support to people with cancer and their family and friends.

The centre offers a calming and beautiful space, a professional team of support staff, and the opportunity to talk and share with a community of people who have been through cancer too.

Maggie's centres are warm, friendly and informal places full of light and open space, with a big kitchen table at the heart of the building. Maggie's West London is located in the grounds of Charing Cross Hospital but is independent of our hospital.

The centre is open Monday to Friday, 09.00-17.00. For more information please call 020 7386 1750.

Macmillan Support Line

The Macmillan Support Line offers confidential support to people living with cancer and their loved ones. This support line is a national line provided by Macmillan and is independent of our hospital.

The Support Line is open every day, 08:00 to 20:00. Please call: 0808 808 000 or visit www.macmillan.org.uk

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net
Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk