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, but aims to help you understand more about what is discussed.

The two specialist centres providing a service for the treatment and monitoring of ovarian germ cell cancer in the UK are Charing Cross Hospital, London and Weston Park Hospital, Sheffield. Both centres work closely with your local hospital, and it may be that you can have some of your treatment in your local hospital.

During your time at Charing Cross Hospital you will meet members of the ovarian germ cell team, including:

- consultant medical oncologists
- consultant gynae-oncologist
- clinical nurse specialists
- the manager for the choriocarcinoma and ovarian germ cell tumours cancer service
- consultant radiologist
- counsellor

What is cancer - what is a tumour?

The organs and tissues of the body are made up of millions of different cells. Cancer is a disease of our cells. Nearly all cells, even if they have different functions, repair and reproduce in the same way. All cells divide and normally they do this in an orderly and
controlled way. If for some reason the process gets out of control, the cell will continue to divide and become a mass which is called a tumour. Tumours can either be benign (non-cancerous) or malignant (cancerous). A benign tumour is made up of cells that don’t spread to other parts of the body. A malignant tumour (cancer) consists of cells that can spread (metastasize) to other parts of the body and invade the tissue around the original tumour.

**What is ovarian germ cell cancer?**

To understand this better we first need to look at the ovaries. Where are they, what do they do?
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, 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. 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, but 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. Many of these are non-cancerous (benign), but some are cancerous. 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 also occur in women in their 60s.

Doctors usually remove germ cell cancers with surgery and this may be all the treatment you need if the cancer is small and easy to remove. However you will usually need 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. Even cancers that have spread can still be successfully treated with chemotherapy.
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 also 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/mature teratoma**
A dermoid cyst is benign (non-cancerous) and is also known as a mature teratoma. This is the most common kind of ovarian germ cell tumour. Very occasionally a small part of a dermoid cyst can become malignant (cancerous).

**Dysgerminomas**
This is a malignant form of germ cell tumour and usually affects only one ovary, but can sometimes affect both. 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 that normally affect only one ovary. There are many technical names for this family of tumours including teratoma, 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, and 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 tests and investigations at your local hospital. If appropriate your local hospital may have removed 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. Once the ovary has been removed, it is sent for examination under a microscope. The doctor can then tell whether it’s 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, a process which 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 most appropriate treatment for you.

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

**Referral to a specialist centre**

All germ cell tumours of the ovary in the UK are now registered with a specialist centre, either in London or Sheffield for monitoring and follow-up.

This allows every patient to benefit from specialist advice. Our consultants are specially trained and have lots of experience in caring for ovarian germ cell patients.

Once registered with a specialist centre, some tests you have had previously will continue, either at the specialist centre or locally.

The tests you may need to continue taking are described below.

**Blood tests**

You may have a test to see whether or not chemicals called tumour markers are being released into the bloodstream. 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 AFP (alpha-fetaprotein) and HCG (human chorionic gonadotrophin) and CA 125 (cancer antigen 125). A marker is a substance found in the blood when a cancer is present. They can also be called tumour markers.
**Ultrasound scan**
A small device like a microphone, which produces sound waves, is moved over the abdomen. The sound waves are converted into a picture by a computer to clearly show the ovaries.

Ultrasound scans can also be carried out vaginally. A small device (about the size of a tampon) is put into the vagina. This also produces sound waves, which are converted into a picture by a computer.

**Computerised tomography (CT) scan**
A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It’s important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to this injection.

**Magnetic resonance imaging (MRI)**
MRI scanners use strong magnetic fields and radio waves to produce detailed images of the inside of the body on a computer. An MRI scanner is a large tube that contains a series of powerful magnets. You lie inside the tube during the scan. As the scanner uses strong magnets it is important to tell your nurse or doctor if you have any implanted medical devices (such as a pacemaker) or any metal fragments lodged in your eyes or body. Once inside the scan
you will need to lie still for around 15 – 40 minutes. It can be quite noisy.

Treatment for germ cell tumours

Ovarian germ cell is now 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.

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, which won't affect a woman's 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 an infusion (drip) into a vein in your arm (intravenously). Often a combination of chemotherapy drugs is given. Sometimes it isn't necessary to follow the surgery with chemotherapy if the tumour is discovered at a very early stage. Also, sometimes chemotherapy is given before surgery to shrink a tumour and make it more operable.
If chemotherapy is necessary, the main part is usually given every three weeks, for up to four sessions of treatment. This will typically require admission to hospital for three nights and a top-up treatment as a day patient each week. Occasionally, more frequent two weekly admissions for treatment are needed, lasting up to five days.

**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 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 and scans. These tests will continue to be required 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 let your GP know as soon as possible.

**Fertility**
One of the main aims of treatment in young women is to preserve fertility, and this is taken into consideration when treatment is being decided. 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 will still produce eggs, but if both 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 that you will be unable to carry a pregnancy.

If your consultant decides you need chemotherapy, your fertility will be discussed and you may be offered fertility preservation. Fertility preservation means stimulating your ovaries to produce eggs and then freezing embryos (fertilised eggs) if you have a partner, or unfertilised eggs, if you don’t. It can take three to six weeks depending where you are in your menstrual cycle.

You will only be offered fertility preservation if:

- you do not already have a family
- it is clinically acceptable to briefly delay your chemotherapy while the procedure is carried out, and
- the treatments you are to receive are thought likely to significantly reduce your chances of future pregnancy

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 key worker about the help available both at your treatment centre and nearer to home.

Who is my key worker?

Your key worker will be any of the clinical nurse specialists (CNSs). They are nurses who are specially trained to give individualised
care and support, in this case, to patients following a diagnosis of ovarian germ cell cancer.

What do I do if I want this support?

Please do contact us, we are here to help. You can get in touch via the Macmillan navigator service, details of which are listed on the next page. When you are in hospital one or more of the CNSs will visit you daily. You can also ask the ward staff to contact one of them to come to the ward and see you.

Contacting the ovarian germ cell team

Imperial College Healthcare NHS Trust has a Macmillan navigator service for access to your CNS and other members of the clinical team.

Navigators can also help with queries and provide a range of other information, help and support relating to your care.

The service is available Monday to Friday 08.00–18.00. Telephone: **020 3313 0303**

Other useful contact numbers

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<thead>
<tr>
<th>Ward 6 south</th>
<th>020 3311 1920</th>
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<tbody>
<tr>
<td>6 east chemotherapy day care unit</td>
<td>020 3311 7618</td>
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<tr>
<td>Tumour marker screening office</td>
<td>020 3311 1409</td>
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Other sources of information and support

Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith Hospitals
The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide emotional and practical support, as well as signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs with dedicated Macmillan information professionals.

The information centre is located on the ground floor of Charing Cross Hospital and is open (except bank holidays):

- Monday and Friday, 09.00–17.00
- Tuesday, Wednesday, Thursday 09.00–16.00

Telephone: 020 3313 0171

The infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital and is open (except bank holidays):

- Monday and Tuesday 09.00-17.00
- Wednesday, Thursday, Friday 09.00-16.00

Telephone: 020 3313 4248

Maggie’s Cancer Caring Centre
Maggie’s is a cancer charity that provides emotional, practical and social support that people with cancer may need. This drop-in centre combines striking buildings, calming spaces, professional experts offering support, and the ability to talk and share experiences with a community of people who have been through
similar experiences. Maggie’s West London is located in the grounds of Charing Cross Hospital but please note it 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 Cancer Support Helpline**
This is a free helpline for people affected by cancer who have questions about cancer, need support or just someone to talk to. It is open from Monday to Friday, 09.00–20.00 (interpretation service available). Telephone: **0808 808 0000**

**Information Prescription Service**
This service contains reliable and accurate cancer information to help patients manage their health more effectively. Log onto www.nhs.uk/ips and enter your condition to start using the service.

**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 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte’s & Chelsea hospitals), or **020 3312 7777** (St Mary’s and Western Eye hospitals). You can also email PALS at pals@imperial.nhs.uk. 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 express your concerns in **writing** to:

Complaints department, fourth floor, Salton House, St Mary’s Hospital, Praed Street, London W2 1NY.
Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

We have a free and premium wi-fi service at each of our five hospitals. For further information please visit our website: www.imperial.nhs.uk

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Cancer services
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