

ovacome..
ovarian cancer

Germ cell ovarian cancer



Ovacome is a national charity providing support and information to anyone affected by ovarian cancer.

We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This booklet is part of a series giving clinical information about ovarian cancer.

It describes germ cell ovarian cancer, a rare form of the disease, its symptoms and treatment.



What are germ cell tumours?

Germ cell tumours start in the ovarian cells that develop into eggs (ovum).

The tumours can be cancerous (malignant) or non-cancerous (benign). It is not known what causes them.

Germ cell ovarian cancer is a rare form of the disease. There are around 200 cases in the UK every year making up just two to three percent (two to three in 100) of ovarian cancer cases. Most germ cell tumours are found to be non-cancerous. They are most often found in people aged under 20 but can affect people up to their early 30s. Very rarely they can affect older people.

Germ cell tumours have a high cure rate when treated.

Types of germ cell ovarian tumours

The most common types of germ cell tumour are non-cancerous (benign). These are mature teratomas, also known as ovarian dermoid cysts. They are most common in teenage years and up to age 40.

If your germ cell ovarian tumour is benign, so not a cancer, you will have surgery to remove the tumour. This means you could keep the affected ovary, and the surgeon will leave the other ovary. It is likely that no further treatment will be needed.

If you are diagnosed with a mature teratoma, after treatment you may have follow-up appointments to check whether it re-grows and needs further surgery. This can sometimes happen.

Cancerous forms of germ cell are:

- Immature teratomas
- Dysgerminoma
- Yolk sac tumour
- Non-gestational choriocarcinoma
- Embryonal carcinoma

Symptoms of germ cell ovarian cancer

- Abdominal or pelvic pain
- Abdominal lump
- Abdominal bloating
- Irregular periods
- Post menopausal bleeding
- High temperature – and chills

Symptoms can also include pregnancy-like symptoms such as feeling and being sick. This is because some tumours can make proteins which are very like the proteins made in early pregnancy.

How is germ cell ovarian cancer diagnosed?

If you are having investigations for germ cell ovarian cancer you are likely to be offered blood tests, a biopsy, plus ultrasound, CT or MRI scans and a chest x-ray.

The blood tests will look for tumour markers, which are made by some germ cell cancers and released into the blood. These might include alpha-fetoprotein (AFP), human chorionic gonadotrophin (hCG) and lactate dehydrogenase (LDH). Levels of human chorionic gonadotrophin (hCG) can go up if you are pregnant. So, if you think you may be – or are – pregnant it is important to tell your doctor.

You may also be offered a CA125 blood test.

Treatments for germ cell ovarian cancer

If you have been found to have germ cell ovarian cancer you will probably be recommended to have surgery. This could be the only treatment you need.

If you are aged between 18 and 24 the British Gynaecological Cancer Society (BGCS) recommends that your treatment should be managed jointly between the gynaecology multidisciplinary team (MDT) and the teenage and young adult MDT.

Surgery

Your surgeon, who should be a gynaecological oncologist, will aim to remove the affected ovary and fallopian tube and as little tissue as possible. This is fertility-sparing surgery and afterwards you may still be able to have children. It may be possible to do the operation using keyhole surgery (laparoscopy).

The surgeon will examine the inside of your abdomen for signs of cancer. They may take biopsies (small samples of tissue) to send to the lab to look for cancer cells. They may also wash out your abdomen with saline and send the fluid to be checked.

The surgeon will remove all or some of the cancer depending on how far it has spread. This means they will know the stage of the cancer. Stage 1 is the earliest of four stages. It means the cancer is contained in one ovary. Cancer is also graded from one to three. Grade 1 means the cancer cells are likely to grow slowly.

If you have been diagnosed with stage 1a dysgerminoma or stage 1a grade 1 immature teratoma, this surgery is likely to be the only treatment you need.

Whether or not you are offered chemotherapy afterwards depends on the type, stage and grade of your cancer tumour.

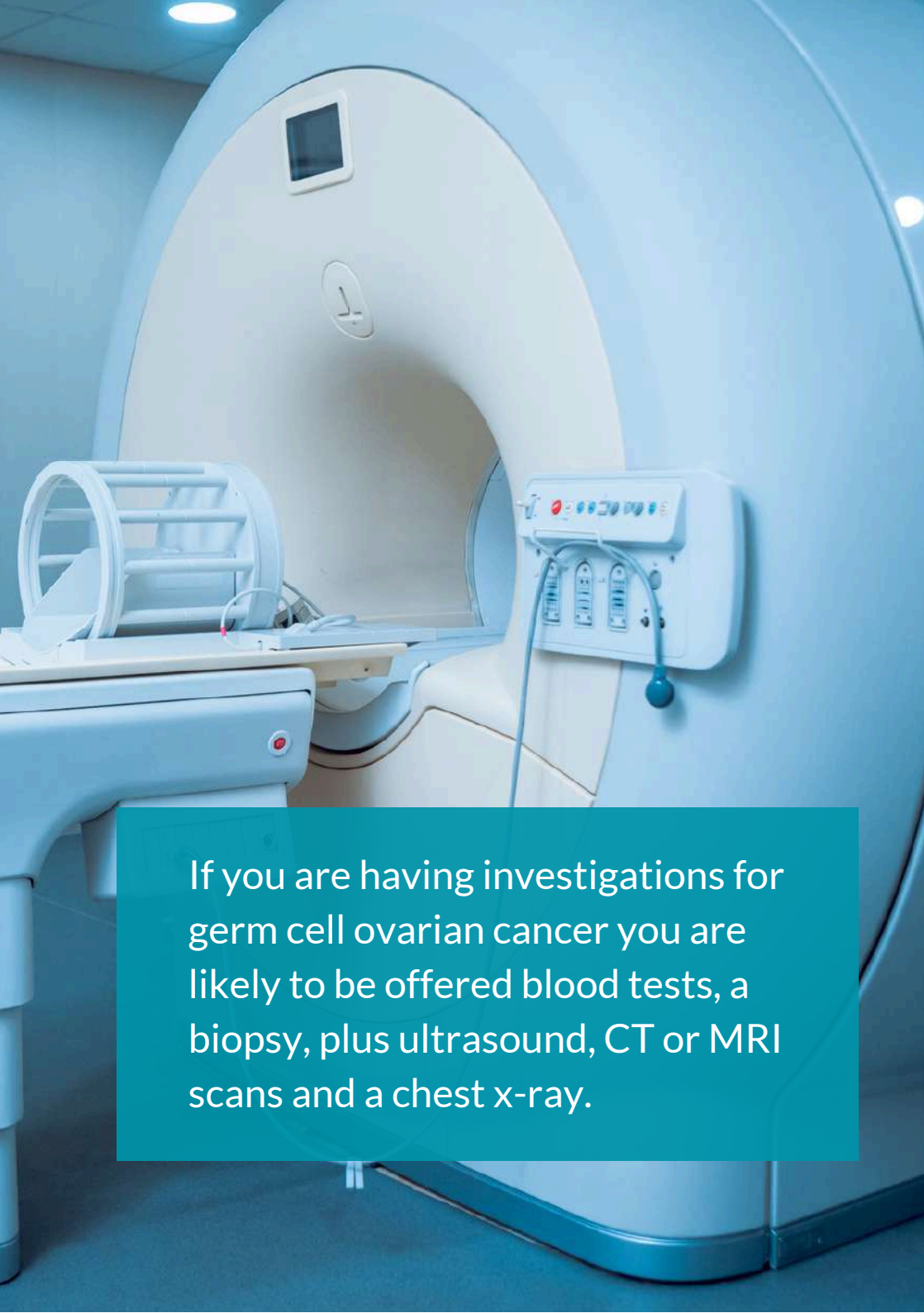
If you are not recommended to have chemotherapy following your surgery your multi-disciplinary team (MDT) will carefully monitor you, to check the cancer does not come back. Your MDT can confirm with you the frequency and type of monitoring you will have.

All ovarian germ cell cancers should be monitored for at least 10 years.

Chemotherapy

You may be given chemotherapy before you have surgery if your cancer is advanced, or you may be offered it afterwards to treat any cancer cells that have been left behind.

Chemotherapy for germ cell ovarian cancer is usually a combination of three drugs: bleomycin, etoposide and cisplatin (platinum chemotherapy), this treatment is known as BEP. You will probably be given three or four cycles after your surgery.



If you are having investigations for germ cell ovarian cancer you are likely to be offered blood tests, a biopsy, plus ultrasound, CT or MRI scans and a chest x-ray.

Longer term side effects

Your fertility

Surgery for germ cell ovarian cancer doesn't usually affect your fertility. If you have one ovary removed, the other one will still be producing eggs so you may still be able to get pregnant.

Your doctor or nurse should talk to you about fertility before your treatment starts. If there is a risk to your fertility you can be referred to a fertility expert.

You may be advised to avoid pregnancy for up to two years after treatment.

If both your ovaries are removed, you won't be able to get pregnant, and your menopause is likely to start straight away. You should be informed about this before your surgery and given support and advice about using HRT and other therapies to relieve symptoms.

Chemotherapy late effects

All chemotherapy drugs can have side effects, which will be discussed with you before you start your treatment. If you experience any side effects, you should tell your team as soon as possible.

Chemotherapy can affect your periods by making them irregular or stopping them completely. It may take a few months for your periods to come back after you finish chemotherapy. It is important to keep using contraception at this time, to avoid an unplanned pregnancy.

After chemotherapy you may experience menopause symptoms. These may start suddenly and be temporary depending on your age. Tell your clinical team if this happens to you.

Some chemotherapy drugs can affect your heart health. You may have been taking the chemotherapy combination BEP. Bleomycin, which is part of BEP, can cause lung problems, coughs or breathing problems. These side effects are experienced by 10 per cent (10 in 100) of users. Tell your team if you become breathless, have changes in your breathing, feel faint, drowsy, confused or very tired due to breathing problems.

Support for younger people

Having cancer at a younger age can feel especially isolating. There is support available for you.

Ovacome runs a monthly online Under 45s support group, details are on our website here: www.ovacome.org.uk/under-45s-group

Shine Cancer Support offers a range of support for people diagnosed with cancer in their 20s, 30s and 40s www.shinecancersupport.org

Trekstock supports people in their 20s and 30s who are diagnosed with cancer www.trekstock.com/

Young Lives vs Cancer supports people diagnosed with cancer up to age 24, and their families www.younglivesvscancer.org.uk/



Surgery for germ cell ovarian cancer doesn't usually affect your fertility. If you have one ovary removed, the other one will still be producing eggs so you may still be able to get pregnant.

Further Ovacome information:

Tests for ovarian cancer www.ovacome.org.uk/tests-for-ovarian-cancer-booklet

Stages of ovarian cancer www.ovacome.org.uk/stages-of-ovarian-cancer-booklet

Surgery www.ovacome.org.uk/surgery-for-ovarian-cancer-booklet

Surgical menopause www.ovacome.org.uk/surgical-menopause-booklet

Chemotherapy www.ovacome.org.uk/chemotherapy-booklet

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information

Reviewed by Michelle Greenwood, Macmillan lead CNS for gestational trophoblastic and ovarian germ cell cancers. Chair of the National Germ Cell Group Charing Cross Hospital, Imperial College Healthcare NHS Trust.

Disclaimer

Ovacome booklets provide information and support. We make every effort to ensure the accuracy and reliability of the information at the time of publication. The information we give is not a substitute for professional medical care. If you suspect you have cancer, you should consult your doctor as quickly as possible. Ovacome cannot accept any liability for any inaccuracy in linked sources.

Version 1 | November 2025 | Date for review November 2028

ovacome..
ovarian cancer

Support line: 0800 008 7054
Office phone: 0207 299 6654
Website: www.ovacome.org.uk
Email: ovacome@ovacome.org.uk

Ovacome is a charity. We receive no government funding and most of our funding is provided by our community of supporters. We want to continue providing free support and information to people when they need it most. If you can, then please help us by making a donation. You can scan the QR code to the right or visit www.ovacome.org.uk/donate



Registered with



Registered Charity Number: **1159682**