ovacome..
ovarian cancer

Granulosa cell tumours

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 gives information about granulosa cell tumours (GCT), a malignant form of sex cord stromal tumours. It describes the causes of GCT, symptoms, diagnosis, treatment and afterwards.

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Patient Information Forum

What are granulosa cell tumours?

Granulosa cell tumours are a type of sex cord stromal tumour. These tumours develop from cells in the ovary that produce hormones. Sex cord stromal tumours (SCSTs) can be cancers (malignant) or non-cancerous (benign).

Malignant forms of SCST are rare. Just five per cent (five in 100) of people diagnosed with ovarian cancer – around 375 people a year – will have a malignant sex cord stromal tumour.

Granulosa cell tumours (GCTs) are the most common form of these malignant tumours.

They can occur at any age, the average age at diagnosis is 50 years old.

There are two types of GCT:

- Adult GCTs (AGCT) are most common and usually diagnosed in middle aged and older people
- Juvenile GCTs (JGCT) usually affect much younger people and are rare

What causes GCT?

The causes are thought to be genetic. Most cases arise when a change has occurred on a gene called FOXL2. This gene helps granulosa cells in the ovary to grow normally, so changes to the gene can allow abnormal cells to develop instead.

We don't know why this happens, but it is not thought to be a change that can be inherited. So, if you are diagnosed with GCT, your family members should not be at an increased risk of developing it too.

Symptoms of GCT

GCT symptoms are similar to other forms of ovarian cancer:

- Bloating in your abdomen (the area between the chest and the pelvis) that doesn't go away
- Pelvic or abdominal pain
- Feeling full more quickly
- Changes in your bowels, such as diarrhoea, constipation
- Needing to urinate more often or more urgently

You may also experience:

- Changes to your periods, they may be irregular, heavy or you have no bleeding
- Bleeding after your menopause
- Breast tenderness or changes
- Early puberty, in young girls

These symptoms can be due to changes in hormone levels caused by the tumour.

Tests and diagnosis

There are blood tests that can help to diagnose GCT such as:

- Inhibin A and inhibin B. Inhibin is a chemical made by granulosa cells that is used as a tumour marker for GCT
- Anti-mullerian hormone (AMH)
- CA125, which is a tumour marker used to diagnose some other forms of ovarian cancer but is less helpful for GCT

You may also be offered an ultrasound scan. This may be a scan when a probe is used on your abdomen, or it may be an internal scan when a small probe is put into your vagina. This can give a much clearer view of the ovaries. You may also be offered a CT scan or an MRI scan.

See more information about tests here:

www.ovacome.org.uk/about-ovarian-cancer/diagnosis/tests-for-ovarian-cancer

Treatment for GCT

Your treatment will depend on the stage and type of GCT you have, your age, whether you have been through the menopause, and whether you want to have children.

Most GCTs are diagnosed early, when they affect the ovaries only, and have not spread. This is stage 1.

The CA125 blood test is a tumour marker used to diagnose some other forms of ovarian cancer but is **less helpful** for GCT.

Surgery

The first treatment is usually surgery which aims to remove as much of the tumour as possible. If your GCT is diagnosed at stage 1a and contained in one ovary, then usually only the affected ovary will be removed. If it is at stage 1b and affecting both ovaries, then both will be removed. This may be the only treatment you need.

You may need chemotherapy if the GCT is stage 1c.This means it affects both ovaries and fallopian tubes, and the sac surrounding the tumour has burst; or the GCT is stage 1c 2, which means it has spread to the surface of the ovary or fallopian tube.

Younger people with juvenile granulosa cell tumour (JGCT) may be offered chemotherapy if their tumour is at stage 1c.

There is more information about staging here:
www.ovacome.org.uk/stages

Chemotherapy and other options

If you need chemotherapy, you may be offered bleomycin, etoposide and cisplatin. This is a combination called BEP. If you are aged over 40 you may be offered etoposide and cisplatin. There are other options that your multidisciplinary team can discuss with you. Your team may also recommend hormone therapy or radiation therapy.

After your treatment

When your treatment is complete you should be monitored regularly as an outpatient by a gynaecologist and/or oncologist. This should include blood tests looking at your levels of tumour markers such as inhibin A and B and AMH. You may also be offered ultrasound or MRI scans.

You may have had your surgery before your menopause. This could result in you having a surgical menopause as your ovaries are likely to have been removed. This means after surgery you may develop menopausal symptoms.

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

As GCT is a hormone producing tumour, hormone replacement therapy (HRT) may not be a suitable treatment for you. Speak to the oncologist or gynaecologist who is monitoring you and ask what your options are, or to be referred to a specialist menopause clinic.

Laura was diagnosed aged 32:

"The last thing I expected was to be diagnosed with cancer, and have to go through a hysterectomy and surgical menopause. A year into the journey, I have a good network of support helping me adjust to menopause. Life-long monitoring was initially daunting, but it is a great reassurance."

If you were treated with fertility-sparing surgery, you will still have one ovary and your womb so your periods should return.

Your fertility

If you were treated with fertility-sparing surgery, you will still have one ovary and your womb so your periods should return. Your remaining ovary will still be producing hormones throughout your menstrual cycle. Your gynaecologist or oncologist may suggest that to get the most accurate results the blood test to monitor your inhibin levels should be taken at the start of your cycle between day one and day three.

Removing one ovary means you could get pregnant. It causes a small reduction in fertility and can bring your menopause forward by a year or two. Some people choose to have their eggs removed and frozen before or after treatment. You can talk to your doctor about this option.

If you become pregnant or are breastfeeding, inhibin levels cannot be monitored at this time as they won't be accurate. Instead, you may be monitored using ultrasound at these times.

Will the GCT come back?

Granulosa cell tumours can come back a long time after your initial treatment. This can be as long as 20 to 30 years afterwards. This means you should have long-term follow up and monitoring.

If it does come back, you may need further surgery followed by more chemotherapy or endocrine (hormone-controlling) therapy.

Linda was diagnosed at 49:

"I was diagnosed pre-menopausal at 49. Being faced with long term or even life-long monitoring seemed hard at first, but I've come to see it as similar to having a mammogram."

For more information see these Ovacome booklets:

www.ovacome.org.uk/stage-1

www.ovacome.org.uk/stage-2

www.ovacome.org.uk/stage-3

www.ovacome.org.uk/stage-4

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

www.ovacome.org.uk/chemotherapy-booklet

www.ovacome.org.uk/coping-with-anxiety-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

Written and reviewed by Dr Charlotte Badescu GP, with a special interest in women's health and early cancer diagnosis, and lived experience of ovarian cancer.

Disclaimer

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Support line: 0800 008 7054
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