

ovacome..
ovarian cancer

Borderline ovarian tumours

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Patient Information Forum

Ovacome is the UK's ovarian cancer support charity.

We provide support and information to anyone affected by ovarian cancer. This includes people who have either been diagnosed with the disease or think that they might be at risk, as well as their friends and family, and healthcare professionals.

Our free support services include:

- Telephone, email, text and instant chat support
- A 24-hour online forum
- Regional support and information events
- Online talks, workshops and support groups
- Expert information resources on ovarian cancer, to support with diagnosis, treatment and beyond

We also raise awareness of the signs and symptoms of ovarian cancer, and work alongside clinicians and researchers to ensure that patient voices are heard in the development of new policy and research on ovarian cancer. **For more information, please visit www.ovacome.org.uk**

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

It is for those diagnosed with borderline ovarian tumours and the issues that may arise.



Borderline ovarian tumours

If you are diagnosed with a borderline ovarian tumour, you can feel confused and uncertain. However, most people who develop this are completely cured by surgery and never need any more treatment.

What are borderline ovarian tumours?

Ovarian cancer develops when cells grow uncontrollably on the surface of the ovary and are able to spread to other organs.

Borderline ovarian tumours arise from the same type of cells, but their growth is much more controlled, and they are usually not able to spread. Small borderline ovarian tumours don't always cause symptoms. They are sometimes found in tests for other conditions. Larger borderline ovarian tumours may cause pain or pressure in your pelvis or abdomen, abdominal swelling, painful sex and vaginal bleeding that is not a period.

A diagnosis of borderline ovarian tumour can be confusing, because you are treated by cancer specialists, but it is not a cancer diagnosis. Most cases of ovarian cancer are found at an advanced stage (stage 3 or 4). This is when the cancer has spread beyond the ovary.

Because borderline ovarian tumours behave in a much less aggressive way, in most people the condition has not spread beyond the ovary when it is diagnosed (stage 1 disease). This means that for those who have had surgery to remove early disease, the risk of it coming back is very small at less than five per cent (five in a hundred).

Follow up

There is ongoing research in to whether people with borderline ovarian tumours should be followed up regularly after their initial surgery. Guidance from BGCS (British Gynaecological Cancer Society) is that follow up is essential in patients who have had fertility sparing treatment. However, the value of follow up is uncertain in patients with early disease who have had both ovaries removed.

www.bgcs.org.uk/wp-content/uploads/2019/05/BGCS-Guidelines-Ovarian-Guidelines-2017.pdf

There is further research being undertaken.

www.sciencedirect.com/science/article/pii/S1521693425001129#fig5

The length and frequency of follow up can vary in different centres. You can discuss your wishes and any concerns you have with your team.

Some people may experience menopausal symptoms after surgery. If you notice changes such as hot flushes, mood shifts, or sleep difficulties, please speak to your oncology team to discuss ways to manage these symptoms.

More difficult cases

There are three situations which can cause greater concern or uncertainty.

1. Borderline ovarian tumours which have spread beyond the ovary.

2. Mucinous borderline ovarian tumours involving the ovary, when tests suggest these could originate from a tumour in the appendix.
3. Stage 1 borderline ovarian tumours in young people treated with limited surgery to keep an ovary. There could be an increased risk of the disease coming back in the ovary you have kept.

Borderline ovarian tumours that have spread beyond the ovary

A small number of people with borderline tumours have disease which has spread, in the form of little seedlings, onto the peritoneal membrane covering other organs in the abdomen.

Surface seedlings

Most of these seedlings do not invade the underlying tissue but are just sitting on the surface. They are sometimes referred to as non-invasive implants. It is rare for them to cause problems, even if they stay after surgery.

We do not know the absolute correct way to care for those with surface seedlings/non-invasive implants of borderline ovarian tumours, because research studies comparing different treatments (including observation) have not been performed. The current guidance is that surgery should aim for complete removal of disease, including the peritoneum.

If the seedlings are invasive into the tissue of the peritoneum this is classified as low grade ovarian cancer.

Low grade ovarian cancer is also treated mainly using surgery although chemotherapy and hormone therapy may also be offered.

For more information see Ovacom booklet Low grade serous ovarian cancer available at www.ovacom.org.uk/low-grade-serous

Mucinous borderline ovarian tumours

Most borderline ovarian tumours are classified as serous from their appearance under the microscope. A smaller number have a different appearance and are called mucinous.

Sometimes a small, undetected mucinous tumour can develop in the appendix and spread to the ovary. This can give the appearance of a primary ovarian tumour, when in fact it is a secondary tumour.

Surface seedlings

It is important to consider this possibility in all cases of mucinous borderline ovarian tumour, so that a separate appendix tumour is not left behind at surgery.

It is difficult to decide the type of ovarian tumour (serous or mucinous) at the time of the operation. Surgeons must carefully inspect the whole abdomen, including the appendix, to look for a hidden primary tumour.

After surgery the pathologist may use special tests to tell apart a mucinous borderline tumour which has arisen from the appendix from one which was originally from the ovary.

Multidisciplinary teams dealing with ovarian tumours should discuss these cases in detail, so they can make sure you receive the correct advice and treatment.

Stage 1 borderline ovarian tumours in young people treated with limited surgery

If you are a young person with a borderline ovarian tumour, you may want to keep an ovary so you can have children. In this situation, a surgeon may remove the affected ovary or just remove the abnormal ovarian cyst (known as ovarian cystectomy) but leave the apparently normal ovary and uterus (womb). The surgeon must examine the abdomen carefully, to check if the tumour has spread. In about 20 per cent (one in five) of these cases, the tumour comes back in the ovary that is left. This means you need regular check-ups after surgery.

Follow-ups may include ultrasound examinations every six months for about two years, then yearly. Later it may be appropriate for those who have had their family to have the remaining ovary removed. This removes the risk of problems in the future and means they will not have to go for follow-ups.

If having children in the future is important to you, it can be helpful to speak with a fertility specialist once a diagnosis of borderline tumour has been confirmed. They can guide you through options such as checking your current fertility (for example, looking at your ovarian reserve) and discussing ways to preserve your fertility, like freezing eggs or embryos. You can find out more about this here: www.ovacome.org.uk/fertility

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:

Miss Dhivya Chandrasekaran, Consultant in Gynaecological Oncology at University College London Hospital (UCLH)

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.

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

Ovacome is here for anyone affected by ovarian cancer with free support, information and community when it's needed most. We receive no government funding, so everything we do is powered by people like you. If you can, please consider donating today. Scan the QR code or visit:

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