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ovarian cancer

Mucinous 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 is for those diagnosed with mucinous ovarian cancer, a rare form of the disease.

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Mucinous ovarian cancer

Mucinous ovarian cancer (MOC) is a rare form of ovarian cancer. It is diagnosed in about three per cent (three in 100) of ovarian cancers, so around 200 people a year in the UK.

What is mucinous ovarian cancer?

Mucinous ovarian cancer is different from the more common, high grade serous form of epithelial ovarian cancer. MOC is most often found in people aged 40 to 50, unlike high grade serous epithelial ovarian cancer which is mostly found in people aged around 60.

It tends to form a large tumour and so may cause symptoms and be detected before it has spread. Sometimes there are borderline ovarian tumour cells mixed in with MOC cells.

You can find out more from Ovacome booklet Borderline ovarian tumours here: https://www.ovacome.org.uk/borderline-ovarian-tumours-booklet

This results in up to 80 per cent of cases (80 in 100) being diagnosed early, at stage 1, so it can often be treated by surgery only, without using chemotherapy.

You can find out more from Ovacome booklet Stage 1 ovarian cancer here: https://www.ovacome.org.uk/stage-1-booklet

MOC sometimes affects a single ovary so fertility sparing surgery, which preserves the unaffected ovary, may be possible. Not all mucinous tumours are cancers, some are found to be benign.

What causes mucinous ovarian cancer?

Mucinous cancer cells secrete mucus, a thick protective fluid. This type of cell is not normally found in the ovaries, but they are found in the stomach, intestines and inner part of the cervix.

This means that if mucinous cancer is found in an ovary it may have arisen in one of these organs. So, the ovary may be a site of metastasis or secondary cancer, while the source of the mucinous cells (the primary cancer) may be in another part of the body, such as the stomach.

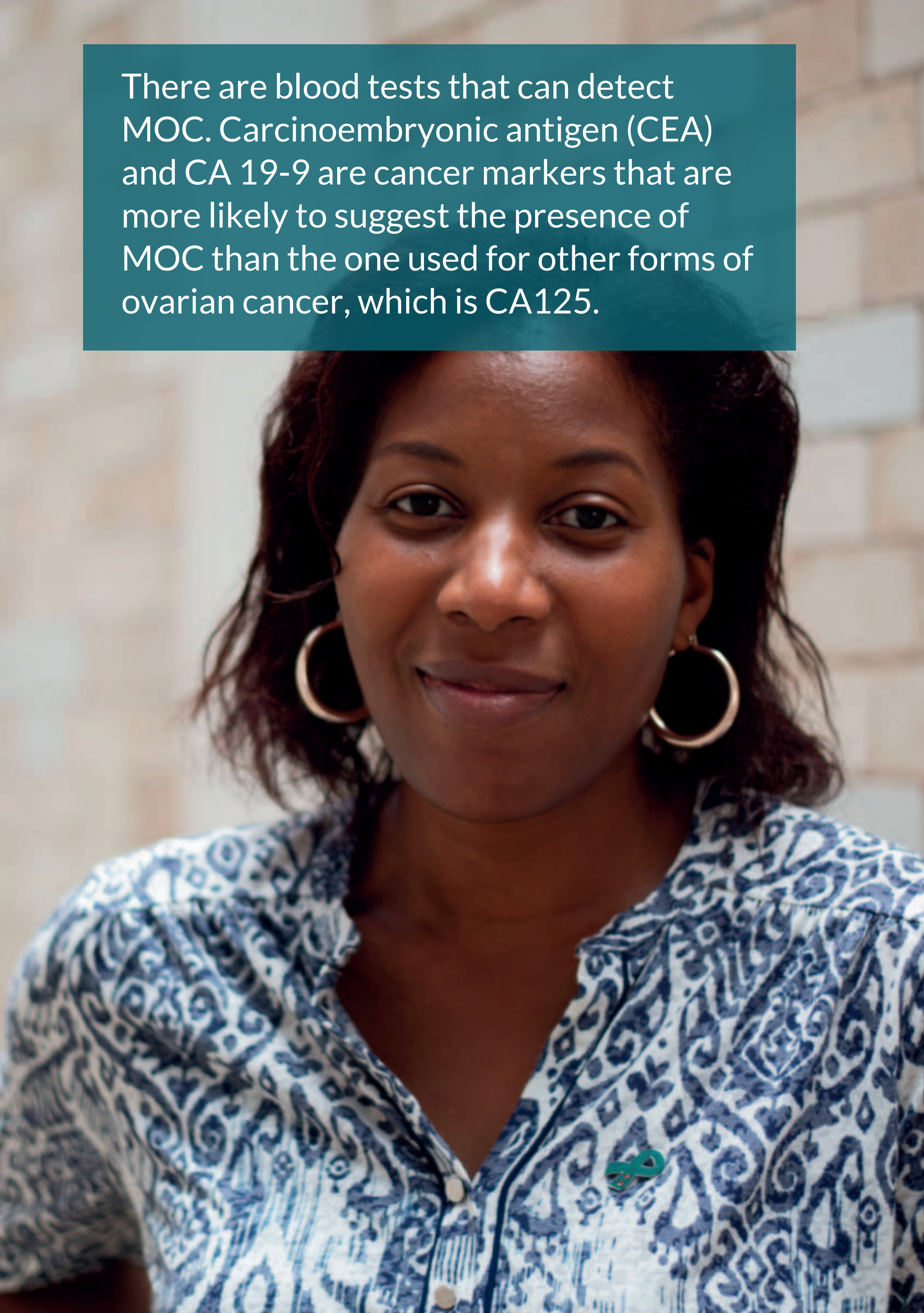
In about 80 per cent of cases (80 in 100) of MOC the tumours arose from another part of the body. This means that only about 20 per cent, (20 in 100) of mucinous ovarian cancer tumours are primary tumours.

MOC does not have the same risk factors as other ovarian cancers, such as age, family history and not having children. The only risk factor that has been suggested in some research is smoking, which is seen as increasing the risk of MOC by a small amount.

How is mucinous ovarian cancer diagnosed?

People with MOC usually notice an abdominal mass that is removed surgically, and a diagnosis is then made. Sometimes there can be significant pain that may come on quite quickly as large masses can twist; this is described as torsion.

There are blood tests that can detect MOC. Carcinoembryonic antigen (CEA) and CA 19-9 are cancer markers that are more likely to suggest the presence of MOC than the one used for other forms of ovarian cancer, which is CA125.



You may then have a trans-vaginal ultrasound when the ultrasound probe is inserted into your vagina, or a CT scan. These scans are to investigate your symptoms and to look for any other tumours.

An MRI scan may also be used to see if the MOC itself is a primary or secondary tumour. This is important to know as treatment may be different for these two types of MOC tumours.

If the MOC tumour is a secondary tumour you may have an examination of your stomach or colon (bowel) to find the primary cancer tumour. This will be using an endoscope, a thin flexible tube with a camera at the end.

Treatment for MOC

Surgery

Like most ovarian cancers, the initial treatment of MOC is surgery. If the cancer has been diagnosed early at stage 1 this may be all the treatment you need.

The operation will remove your ovaries, fallopian tubes, womb, cervix and omentum (a fatty layer in the abdomen). Sometimes surgeons will also remove pelvic and para-aortic lymph nodes (glands at the back of your abdomen). They will also examine your appendix and may remove this as it can be the site of a primary cancer.

The operation will include peritoneal washing. This introduces sterile fluid into the pelvic area which is then removed to see if it has collected any cancer cells.

The surgery aims to remove as much of the cancer as possible and may include peritoneal biopsies being taken.

Like most ovarian cancers, the initial treatment of MOC is surgery. If the cancer has been diagnosed early at stage 1 this may be all the treatment you need.

If your cancer was diagnosed at a later stage, then your surgeons will try to carry out the same operation and aim to remove as much of the cancer as possible. This means a diagnosis can be made and the cancer's spread (stage) can be seen.

MOC can present as a large cyst and there can be a risk of incisional hernia after your operation. This is when an internal organ such as the bowel comes through the incision site. You can discuss this risk with your surgeon.

The identification of an ovarian tumour as a MOC is made by a pathologist who will look at the tumour using a microscope. This process can take a week or longer.

The information from the pathologist will include the type of ovarian cancer you have, how far it has spread and its grade, which is a measure of how fast the tumour is growing.

MOC is also described as having expansile or infiltrative patterns. Having infiltrative patterns can suggest it has spread further, is at a later stage and more likely to recur. However, it is not clear if this means patients with this diagnosis should have more treatment or not.

Gill's story

Gill was diagnosed in 2017 when she found a lump in her abdomen after experiencing fatigue and bloating. She was treated with surgery.

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> “When I was first diagnosed, I felt incredibly scared and isolated. I needed to know more about mucinous ovarian cancer to get some control back into my life.”

I researched as much as I could find, but because MOC is so rare there was very little information. What I did find was often written in medical jargon and hard to understand.

It has been difficult to find a treatment protocol, so I haven't been able to judge whether I'm getting the best care – which is unsettling.

MOC doesn't respond in the same way to CA125 testing as other ovarian cancers, so I've had no way to tell if it has recurred, which is a worry. I've had to ask several times to have other blood tests which can work better with MOC, but I do get them now.

I've also managed to get in contact with other people diagnosed with MOC which has made me feel more supported."

Chemotherapy

After surgery you may be offered chemotherapy. This will probably be platinum-based using the drugs carboplatin and paclitaxel (Taxol) which are used to treat ovarian cancer. However, there is little research on using these drugs for MOC.

In 2019 a US study looked at the benefits of using chemotherapy to treat MOC which had been diagnosed early at stage 1 (when the cancer is still contained in the ovaries). It found no difference in outcomes in people who had received the treatment and those who had not.

MOC is known to have a reduced sensitivity to platinum-based chemotherapy compared to other forms of ovarian cancer. This means it is less clear if patients should have chemotherapy after surgery, particularly if the cancer has been found at an early stage.

In this situation, if you want to take every available treatment option, you could have carboplatin only, which is usually well tolerated.

Chemotherapy should be offered to meet your individual needs and discussed carefully with your clinical team.

Surgical menopause and fertility

If you have not yet experienced your natural menopause and the surgery removed both your ovaries, you will have a surgical menopause. This may happen immediately after your operation. You will also not be able to get pregnant.

You should be able to discuss these issues with your team when your treatment is being planned. If your MOC is thought to be early stage it may be possible to remove a single affected ovary, leaving the other in your body.This may retain your fertility.

If both ovaries are removed, you will be put into the menopause. You can find out more from Ovacome booklet Surgical menopause here: https://www.ovacome.org.uk/surgical-menopause-booklet

Can I use HRT?

You can ask your team, your GP or a menopause specialist if you can use hormone replacement therapy (HRT).If your womb has not been removed, you are likely to be offered oestrogen – only HRT.

There is little research on its use with MOC patients. This is because MOC is rare and there are too few people affected to provide reliable information.

If you have not yet experienced your natural menopause and the surgery removed both your ovaries, you will have a surgical menopause. This may happen immediately after your operation. You will also not be able to get pregnant.

Guidance published by the British Gynaecological Cancer Society and the British Menopause Society states that if you have been diagnosed with epithelial ovarian cancer (MOC is a rare type of this) the potential benefits and risks of HRT should be discussed with you, and research does not show a risk of the cancer recurring.

You can see the guidance here: https://www.bgcs.org.uk/wp-content/uploads/2024/08/BGCS-BMS-Guidelines-on-Management-of-Menopausal-Symptoms-after-Gynaecological-Cancer.pdf

What about treatment in the future?

At present there is no evidence of better treatment options for mucinous ovarian cancer than the standard platinum-based chemotherapy drugs used in other forms of the disease.

There have been no successful clinical trials that have only included people with MOC. This is because very few people are affected, and trials have not been able to include enough patients to produce reliable results.

Some of these trials have tested the use of chemotherapy drugs that are used to treat bowel cancer, which is often mucinous.

Researchers are looking at the roles of gene mutations that are sometimes present in MOC tumours but are different from those associated with other forms of ovarian cancer. These include KRAS and HER2.

Research has found little evidence to suggest that immune-boosting drugs would be effective in the treatment of MOC. More research is needed, including research on the genetics of MOC.

At present there is no evidence of better treatment options for mucinous ovarian cancer than the standard platinum-based chemotherapy drugs used in other forms of the disease.

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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 of 0800 008 7054 Monday to Friday 10am to 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.

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Disclaimer

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