

Understanding NICE guidance

Information for people who use NHS services

Recognition and initial treatment of ovarian cancer

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and early treatment of women with suspected or confirmed ovarian cancer in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for women with ovarian cancer but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe ovarian cancer or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 14. Medical terms printed in bold type are explained on page 13.

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The advice in the NICE guideline covers:

- Women (18 years and older) who have, or are suspected of having, types of ovarian cancer called epithelial ovarian cancer (the most common type), fallopian tube cancer, primary peritoneal cancer or borderline ovarian cancer.

It does not cover:

- Girls and young women under 18.
- Women with types of cancer called pseudomyxoma peritonei, germ cell tumours of the ovary, or sex cord stromal tumours of the ovary.
- Further treatment for women with ovarian, fallopian tube or peritoneal cancer that has come back ('relapsed') after initial treatment.
- Women with cancer that has spread to the ovary or peritoneum (the membrane that lines the inside of the abdomen) from other parts of the body.

Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain ovarian cancer and the possible treatments for it. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance decision' (known as a 'living will' in the past) in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/consent) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.publicguardian.gov.uk In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government (www.wales.nhs.uk/consent).

In an emergency, healthcare professionals may give treatment immediately, without obtaining your informed consent, when it is in your best interests.

Ovarian cancer

Women have two ovaries. The ovaries produce an egg every month in fertile women, and also produce the female sex hormones oestrogen and progesterone.

Ovarian cancer is the fifth most common cancer in women in England and Wales. It mostly affects women over 50, but it can occur in younger women. There are several types of ovarian cancer, depending on which parts of the ovary are affected. Most women with ovarian cancer have a type called epithelial ovarian cancer, in which the cancer starts in the cells that cover the surface of the ovary.

The symptoms of ovarian cancer can be vague and similar to those associated with other conditions. However, there are a number of symptoms that do suggest ovarian cancer if they are experienced frequently and/or last a long time (see page 5).

Most women with ovarian cancer are treated with a combination of surgery and **chemotherapy**.

What should happen when you see your GP

First steps

When you visit your GP with symptoms that are causing you concern, he or she should talk with you about them and offer you a physical examination.

Your GP should offer you tests if you have had one or more of the following symptoms for a while, or they occur frequently (particularly more than 12 times a month). This is especially the case if you are 50 or over. These symptoms are:

- a long-lasting 'bloated' feeling in your **abdomen**
- loss of appetite or feeling full quickly
- pain in your abdomen or **pelvic area**
- needing to pass urine urgently or more often than usual.

Other symptoms can also be associated with ovarian cancer. Your GP may offer you tests if you are constantly feeling very tired, have been losing weight for no obvious reason or have had changes in bowel habit (for example, constipation or diarrhoea).

If you are 50 or over and have had symptoms over the last 12 months that are similar to those of **irritable bowel syndrome (IBS)**, your GP should offer you tests to check for ovarian cancer. This is because it is unusual for a woman of this age to develop IBS if they have not had it before.

Your GP should refer you urgently (within 2 weeks) to see a **gynaecologist** who specialises in cancer if they identify certain signs when they examine you. These include a build-up of fluid in your abdomen, or a lump in your abdomen or pelvic area that is not a result of **fibroids**.

If, after examining you and discussing your symptoms, your GP thinks that you do not have ovarian cancer, they should advise you to come and see them again if your symptoms continue or become more frequent.

Tests that your GP may do

If your symptoms suggest there is a chance that you could have ovarian cancer, your GP should offer you a blood test, to measure the levels of a protein called **CA125** in your blood.

Having a high level of CA125 doesn't necessarily mean you have ovarian cancer. Levels of CA125 can also be raised in women who have other conditions, and some healthy women have naturally high levels. But if your CA125 is increased to a level that may suggest ovarian cancer, your GP should arrange for you to have an ultrasound of your abdomen and pelvis.

If the ultrasound suggests that further tests are needed, your GP should refer you urgently (within 2 weeks) to see a gynaecologist who specialises in cancer.

You should not be referred to a gynaecologist at this stage if your CA125 levels are normal, or if you have raised CA125 but the ultrasound doesn't indicate that further tests for ovarian cancer are needed. Your GP should check to see whether anything else may be causing your symptoms – this might involve other tests. If there is no apparent cause of your symptoms, your GP should advise you to come back to see them again if the symptoms continue or become more frequent.

Questions you might like to ask your GP

- Please tell me more about ovarian cancer.
- Do my symptoms suggest that I might have ovarian cancer?
- What tests might be appropriate for me?
- What are the possible benefits and risks of having the tests?
- What do these tests involve, and where will they be carried out?
- How long will I have to wait until I have the tests, and how long will it take to get the results?
- What might it mean if my CA125 levels are raised?
- If you think that I don't have ovarian cancer, what else might be causing my symptoms?
- What should I do if my test results are normal but my symptoms continue?
- Why do you think I need to be referred to see a gynaecologist who specialises in cancer?

What to expect when you see a gynaecologist

At your hospital appointment, you should see a gynaecologist who specialises in cancer. Your blood CA125 levels should be measured and an ultrasound of your abdomen and pelvis carried out if you have not already had these tests. If you are under 40, you should also have blood tests that can give more information about the type of ovarian cancer you might have.

If your gynaecologist thinks that the results of your CA125 test and ultrasound indicate that you may have ovarian cancer, they should refer you to a specialist care team of healthcare professionals who are experienced in treating women with ovarian cancer. This is sometimes called a specialist multidisciplinary team, or MDT for short. You should be offered a type of scan called a **CT scan**. This shows a clearer picture of your ovaries than an ultrasound does, and will help to confirm whether you have ovarian cancer. You should not usually be offered a scan called an MRI scan for assessing possible ovarian cancer.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

Questions you might like to ask about tests

- What tests do you recommend for me?
- What are the possible risks of having these tests?
- What are you looking for?
- Please explain what a CT scan involves.
- When will I get the test results?
- Will the tests show whether I have ovarian cancer?

What if I am diagnosed with ovarian cancer?

Getting a diagnosis of cancer can be frightening and confusing. If you are diagnosed with ovarian cancer, your doctor or nurse should offer you information (including written information) about the disease and its possible effects on your everyday life. You might not want lots of detailed information straight away, but it should be available when you do want it. It should cover the following subjects:

- the 'stage' of your disease (see the box on page 9) and treatments that might be appropriate for you
- how to manage the effects of the cancer and of any treatments you choose to have, so that you feel as well as possible
- how your diagnosis may affect sexual relationships and sexual activity
- how surgery for ovarian cancer may affect your ability to have children
- whether **hormone replacement therapy (HRT)** might be suitable for you (this is because surgery to remove your ovaries will mean that you start the menopause if you haven't done so already, and HRT can help with symptoms)
- the chances of family members getting ovarian cancer in the future
- how to deal with emotions such as sadness, depression and anxiety
- where you can get support, including details of support groups.

Questions about ovarian cancer

- Where can I find more information about ovarian cancer?
- What treatments are available?
- Are there any local or national support organisations for women with ovarian cancer?
- Can you provide any information for my family/carers?

Questions for family members and friends

- What can I/we do to help and support the person with ovarian cancer?
- Is there any additional support that I/we as carer(s) might benefit from or are entitled to?

Treatments for ovarian cancer

The tests described on page 7 will give your specialist a good idea of whether you have ovarian cancer. Sometimes, however, it may not be possible to confirm a diagnosis of ovarian cancer until you have had surgery.

The tests may also provide some information about the 'stage' of the cancer – that is, how far it has spread. The stage of the cancer will affect the types of treatment you will be offered.

There are four stages of ovarian cancer, which are described in the box below. Stage I cancer is also called 'early' ovarian cancer, and stages II to IV are called 'advanced' ovarian cancer. Often the stage of the cancer can only be confirmed by surgery.

Stages of ovarian cancer

- Stage I: the cancer is affecting only the ovaries.
- Stage II: the cancer is also outside the ovaries, but still within the pelvic area.
- Stage III: the cancer is also outside the pelvic area – in the lining of the abdomen and/or in abdominal organs such as **lymph nodes**.
- Stage IV: the cancer is also in other parts of the body, such as the liver or lungs.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

Treatments for suspected early (stage I) ovarian cancer

Surgery

Virtually all women with early ovarian cancer will be offered surgery as their main treatment. The aim of surgery is to remove all signs of ovarian cancer. The NICE guideline does not make recommendations about all aspects of surgery for ovarian cancer. Members of your specialist care team should explain what is involved, and talk with you about the various treatment options. You can also get more information from the organisations listed on page 14.

The NICE guideline does say that if you appear to have stage I ovarian cancer, the lymph nodes in your abdomen should be checked to make sure that the cancer hasn't spread to them. But a procedure called systematic retroperitoneal lymphadenectomy (removal of all of the lymph nodes from the abdomen) should not be carried out as part of standard surgery for women who appear to have stage I cancer.

Chemotherapy

The cancer cells that are removed during surgery will be checked to assess the risk of the cancer coming back. Your specialist should talk with you about whether chemotherapy is suitable for you (depending on your level of risk).

You should not be offered chemotherapy after surgery if you had stage I cancer that has a low risk of coming back.

If you had stage I cancer that has a high risk of returning, you should be offered chemotherapy with a drug called carboplatin.

If there is uncertainty about the risk of your cancer returning, your specialist should talk with you about the possible benefits and side effects of chemotherapy, to help you make a decision about whether to try this treatment.

Treatments for advanced (stages II to IV) ovarian cancer

Most women with advanced ovarian cancer will be offered surgery followed by chemotherapy. Sometimes, however, you may be offered chemotherapy before surgery to shrink the tumour, or surgery might not be suitable if the cancer is very advanced. Members of your specialist care team should talk with you about the treatment options available, taking account of your goals and preferences.

Confirming the diagnosis

If you are being offered chemotherapy before or instead of surgery, your specialist should first confirm the diagnosis of ovarian cancer by checking a small amount of tissue taken from your abdomen. This is called a tissue diagnosis. The tissue should usually be obtained by a procedure called **percutaneous image-guided biopsy**. Another procedure called **laparoscopic biopsy** may be used instead if it is more suitable for you. Occasionally, a technique called cytology (which involves checking cells taken from the abdominal fluid) may be used for tissue diagnosis.

Very rarely, you may be offered chemotherapy without a tissue diagnosis. Your specialist should talk with you about the benefits and risks of starting chemotherapy without having a tissue diagnosis.

Surgery and chemotherapy

The aim of surgery is to remove all signs of ovarian cancer, whether the surgery takes place before or after chemotherapy.

You should not be offered intraperitoneal chemotherapy – where the chemotherapy is given directly into the abdomen rather than into a vein – unless you are asked to take part in a **clinical trial** of this type of treatment.

The NICE guideline does not include full details about surgery and chemotherapy for women with advanced ovarian cancer. Members of your care team should talk with you about what the treatments involve, including the benefits and risks associated with them.

Questions you might like to ask about surgery

- Why are you recommending surgery?
- What will it involve?
- What are the possible benefits and risks?
- How long will I be in hospital for?
- Will the surgery get rid of all of my cancer? If not, what other treatments might I have?
- What will happen if I choose not to have surgery?

Questions you might like to ask about chemotherapy

- Please tell me more about chemotherapy for ovarian cancer.
- Why are you recommending chemotherapy?
- What is a cycle of treatment? How many treatment cycles will I have?
- What are the possible side effects of chemotherapy?
- What can you offer me to help me to cope with the side effects?
- Might there be any lasting harm resulting from chemotherapy?
- Are there other drugs I can try if my cancer comes back after the first course of chemotherapy?
- Do you think I should have chemotherapy before surgery?
- What if I choose not to have chemotherapy?

Explanation of medical terms

Abdomen The part of the body between the chest and the pelvis. It contains many of the body's organs, such as the stomach, intestine, liver and kidneys.

CA125 A protein that most women have in their blood. The level of CA125 may be higher in women with ovarian cancer because it is sometimes produced by ovarian cancer cells. However, the level of CA125 can also be raised in women who have other conditions.

Chemotherapy A type of treatment that uses anti-cancer drugs to destroy cancer cells. A course of chemotherapy normally involves several cycles of treatment.

Clinical trial Clinical trials test new treatments to see how well they work and what their side effects are.

CT (computerised tomography) scan A scan that makes a picture of a part of the body by taking a series of X-rays.

Fibroids Non-cancerous growths in the womb (uterus). Fibroids are most common in women under 50.

Gynaecologist A doctor who specialises in conditions and diseases that affect women and their reproductive systems.

Hormone replacement therapy (HRT) Treatment that helps with the symptoms of the menopause by 'topping up' low levels of the female sex hormones.

Irritable bowel syndrome (IBS) A common gut disorder, the exact causes of which are not known. Symptoms include abdominal pain or discomfort that can be relieved by going to the toilet (passing stools), changes in bowel habit (constipation or diarrhoea) and abdominal bloating.

Laparoscopic biopsy A small operation under general anaesthetic in which a thin fibre-optic tube called a laparoscope is inserted into the abdomen through a small cut. This enables the doctor to take a biopsy.

Lymph nodes A network of glands found throughout the body that are involved in fighting infection and cancer.

Pelvic area The part of the body below the navel (belly button) and above the hips.

Percutaneous image-guided biopsy A procedure carried out under local anaesthetic in which tissue samples are taken by inserting a needle through the skin.

More information

The organisations below can provide more information and support for women with ovarian cancer. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- CancerHelp UK (the patient information website of Cancer Research UK), 0808 800 4040
www.cancerhelp.org.uk
- Macmillan Cancer Support, 0808 808 0000
www.macmillan.org.uk
- Ovacome, 0845 371 0554
www.ovacome.org.uk
- Ovarian Cancer Action, 0300 456 4700
www.ovarian.org.uk
- Target Ovarian Cancer, 020 7923 5470
www.targetovarian.org.uk
- The Eve Appeal, 020 7299 4430
www.eveappeal.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see

www.nice.org.uk/AboutGuidance

*This booklet and other versions of the guideline aimed at healthcare professionals are available at **www.nice.org.uk/guidance/CG122***

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2505). The NICE website has a screen reader service called *Browsealoud*, which allows you to listen to our guidance. Click on the *Browsealoud* logo on the NICE website to use this service.*

We encourage NHS and voluntary organisations to use text from this booklet in their own information about ovarian cancer.