

Cancer of unknown primary

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about the care and treatment of people with cancer of unknown primary that is set out in NICE clinical guideline 104.

Does this information apply to me?

Yes, if you are an adult with suspected or diagnosed cancer of unknown primary, including if you have been treated for cancer before.

In this guideline 'cancer of unknown primary' refers to a particular type of cancer, called carcinoma.

No, if you are:

- a child (under 18) who has cancer of unknown primary
- an adult with cancer, or are likely to have cancer, that has spread (also called metastatic cancer) with a known site of primary origin
- an adult with cancer that is not carcinoma (for example lymphoma, melanoma, sarcoma).

Your care

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 information, please talk to a member of your healthcare team.

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the [NHS Constitution](#). 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 discuss with you options for diagnosing your condition and possible treatments. 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' (formally known as a 'living will'), 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 and Social Care's reference guide to consent for examination or treatment](#) and the [Office of the Public Guardian's code of practice for the Mental Capacity Act](#). In Wales healthcare professionals should follow [advice on consent from the Welsh Government](#).

Cancer of unknown primary

When some of the cells in an organ or tissue of the body start to grow in an uncontrolled way, a cancer forms. The organ or tissue where the cancer first starts to grow is known as the primary cancer. But cancer can spread from this primary site to other parts of the body. When cancer spreads it forms secondary cancers (also known as metastases). Commonly affected areas include the liver, the lungs or the bones, but other areas may be affected too.

In most people the primary cancer is easily found with tests such as blood tests, X-rays and scans. But even after tests, sometimes it is not possible to tell where the cancer has come from. This is known as 'cancer of unknown primary'.

There are many different types of cancer of unknown primary and many possible treatments. Because of this, diagnosis may not be quick or straightforward. Healthcare professionals will usually want to try and find out as much as they can about where the cancer has come from to make treatment as effective as possible.

Questions you might like to ask your healthcare team

- Please can you tell me more about cancer of unknown primary?
- What happens if you can't find out where the cancer has started?
- Are there any organisations providing information and support that could help me?

- Can you provide any written information for my family or carers?

Referral to a specialist team

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

If it is suspected that you may have cancer of unknown primary, you should be referred to a member of the cancer of unknown primary team (CUP team) as soon as possible. If you are staying in hospital this should be by the end of the next working day. If you are at home or in residential care, this should be within 2 weeks.

Support during your care

A member of the CUP team, usually the key worker or CUP specialist nurse, should meet you soon after referral and be in contact with you regularly. The key worker will help to coordinate your care, including any tests, investigations or treatment, and will keep your GP informed. You should be able to contact your key worker or the CUP team whenever you need to, whether you are in hospital or at home.

Your key worker should make sure that you, and if appropriate your carers, can get information, advice and support about diagnosis, treatment, palliative care and any spiritual, psychological and emotional concerns. Your key worker should also act as an advocate for you, putting across your views about your treatment and care to other members of the team.

A member of the CUP team should make sure your symptoms are being managed, for example, with effective pain relief.

Assessment

A member of the CUP team should ask you about your medical history and, with your permission, they should carry out a physical examination. You should be offered blood and urine tests, which will give the team more information about your general health.

Deciding about tests and investigations

Your key worker or another member of the CUP team should explain to you that, with your permission, further tests and investigations will be offered to try and find out where your cancer started. One of the most important investigations is a biopsy (see box below), which shows what type of cancer you have. This is so that you can be offered the most appropriate treatment, depending on your health at the moment. The CUP team member should also tell you about any side effects and the possible benefits of the tests and treatment.

If the results of the tests are not likely to affect which treatment you are offered, or if you decide you do not want to have any treatment, you should not be offered any more tests. This should be discussed with you, and support offered if necessary.

Any further tests and investigations will be offered depending on your symptoms, and are described in the box below.

Tests and investigations

Some of the following tests and investigations may be offered to you:

- Blood tests for tumour markers: detect chemicals made by some types of tumour.
- Biopsy: removes a small piece of tissue from a tumour using a needle or with a small operation. The tissue is checked using a microscope.
- Chest X-ray, and sometimes X-rays of other areas of the body.
- CT scan (computed tomography scan): uses X-rays to produce pictures of an area of the body; dye is often given as a drink or into a vein to improve the pictures.
- Endoscopy: uses a thin flexible tube with a camera on the end to look inside organs like the lungs, stomach or bowel.
- Mammography: an X-ray of the breast.

- MRI scan (magnetic resonance imaging scan): uses a magnet and radiowaves to give detailed pictures of an area of the body.
- PET-CT scan (positron emission tomography–computed tomography scan): uses a small amount of radioactive dye injected into a vein to show any abnormal areas in the body.
- Ultrasound: a scan using sound waves to produce pictures of an area of the body.
- Video-assisted thoracoscopic surgery (VATS): a small operation using keyhole surgery, to look at the surface of the lung.

Questions you might like to ask about the tests and investigations

- Please can I have more details about the tests or investigations that I've been offered?
- What is this test or investigation for?
- What if I decide not to have the tests or investigations?
- Where will these be carried out? Will I need to have them in hospital?
- Will the test or investigation be painful? Are there any risks or side effects?
- How long will I have to wait until I have the test or investigation?
- How long will it take to get the results?

Diagnosis

In the NICE guideline, a person is said to have 'malignancy (or cancer) of undefined origin' when cancer of unknown primary is first suspected, but only a few tests have been carried out.

The diagnosis may change to 'provisional cancer of unknown primary' when basic tests and investigations are completed, but further special investigations might still be needed. If the primary cancer is identified, then the person can be offered treatment under the care of a team specialising in that particular type of cancer.

If all the relevant tests and investigations have been carried out and the site of the primary cancer still cannot be found, 'confirmed cancer of unknown primary' is diagnosed. Although tests and investigations sometimes may not identify the primary cancer, they can help healthcare professionals decide on the best treatment to offer.

Deciding about tests and treatment after diagnosis

A member of the CUP team should talk with you, and your carers if you wish, about factors that could affect the outcome of your treatment. These are called your prognostic factors, and include the stage of your disease and whether you are well enough for treatment.

A member of the CUP team should help you decide about having further tests and treatment after diagnosis. Sometimes having more tests won't make a difference to the treatment you are offered, and this should be discussed with you, and support offered if necessary.

You may decide that you do not want to have any treatment, in which case you should not be offered any more tests. Your key worker or another member of the CUP team should talk with you again about palliative care, which aims to control your symptoms and help you remain as comfortable as possible. It is care designed to help not only with your physical needs, but also with psychological, social and spiritual needs.

Treatment

If tests and investigations have not found the primary cancer, when offering you treatment the CUP team should take into account a number of factors. They should consider where your secondary cancer is, whether you are likely to benefit from treatment, whether you are well enough to manage any side effects of the treatment and your personal preferences about treatment options.

If your secondary cancer is confined to one small area of the body, then you may be able to have more specialised treatment, such as surgery or radiotherapy. If this is the case you

will be referred to a team which specialises in treating such tumours.

You may be offered treatment such as chemotherapy, surgery, radiotherapy, or a combination of these to treat your secondary cancer. If you are offered chemotherapy, it may be possible for you to take part in a clinical trial if you want to.

Questions you might like to ask about treatment

- Why have you decided to offer me this particular type of treatment?
- If you find out where the primary cancer is, will my treatment change?
- What will the treatment involve?
- What effects might the treatment have on my symptoms and everyday life? What sort of improvements might I expect?
- How effective is the treatment likely to be in the short and long term?
- Are there any side effects or risks associated with this treatment?
- Is there some written material (like a leaflet) about the treatment that I can have?
- What if I choose not to continue treatment, or choose not to have any treatment?
- Can I take part in a clinical trial?

More information

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

- [Cancer Research UK](#) (the patient information website of Cancer Research UK), 0808 800 4040
- [Cancer of Unknown Primary \(CUP\) Foundation](#) – Jo's friends
- [Macmillan Cancer Support](#), 0808 808 0000

- Rarercancers.org.uk, 0800 334 5551

You can also go to NHS Choices (www.nhs.uk) for more information.

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Accreditation

