

Understanding NICE guidance

Information for people who use NHS services

Advanced breast 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 treatment of patients with advanced breast 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 patients with advanced breast cancer but it may also be useful for their families, carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It describes what NICE has said about the care you should be offered and what this means for you. It does not explain advanced breast cancer or its treatment in detail, neither does it describe every aspect of diagnosis, treatment and care. Your specialist and your healthcare team should discuss these with you. The organisations listed on page 15 can give you, your family and carers general information about advanced breast cancer. There are examples of questions you could ask throughout this booklet to help you.

Contents

| | |
|--------------------------|----|
| Your care | 3 |
| Advanced breast cancer | 4 |
| Support during your care | 5 |
| Scans and tests | 6 |
| Treatment | 8 |
| Complications | 14 |
| More information | 15 |
| About NICE | 16 |

The advice in the NICE guideline describes:

- the tests, treatment, care and support that patients with advanced breast cancer should be offered.

It does not specifically describe:

- the care of patients with early breast cancer or those with rare or non-cancerous tumours of the breast.

NICE has produced separate advice for the care of patients with early breast cancer (www.nice.org.uk/CG80).

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain advanced breast cancer and your care simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take into account any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading, understanding or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If you are unable to understand a particular issue or are not able to make decisions for yourself, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Advanced breast cancer

Breast cancer is the most common cancer in women. It also occurs in men, but this is much rarer. About 40,500 women and 260 men are newly diagnosed with breast cancer in England and Wales each year.

Breast cancer happens when some of the cells in the breast start to grow in an uncontrolled way. They form a lump or mass, which may or may not be felt, called the primary cancer or primary tumour. Cancers start in a small area but can spread to nearby organs or tissues, or to more distant parts of the body. They can break off from the tumour and spread through the body.

Breast cancer is described as 'early' if it is only in the breast and the lymph nodes nearby (most often under the arm), and has not spread to other parts of the body. NICE has produced 'Understanding NICE guidance' for patients with early breast cancer and their families or carers. See www.nice.org.uk/CG80. The cancer is said to be 'advanced' if it has spread to other parts of the body or if it has grown directly into other tissues and cannot be completely removed by surgery.

Most breast cancers are discovered in the early stages of the disease. A small proportion of patients with breast cancer already have advanced breast cancer when the disease is discovered.

Support during your care

At all stages throughout your illness and treatment, your healthcare team should offer you the chance to talk about concerns and needs, such as physical, psychological, social, spiritual and financial support. You may have a key worker who will be your main contact throughout your care.

Palliative care is care and support provided by all healthcare professionals in the teams looking after you at home or in hospital. Sometimes it may be necessary for your usual carers to seek assistance from the Specialist Palliative Care Team. The aim of palliative care is to keep you as comfortable as possible. It is care designed to help not only with your physical needs, but also with psychological, social and spiritual problems, which often become more intense and more frequent during serious illness.

Your supportive care should be in line with the recommendations in the NICE cancer service guidance on breast cancer and supportive and palliative care (see www.nice.org.uk/Guidance/CSG/Published).

Your healthcare team should give you as much information as you want in writing or some other form that you can easily understand. You may prefer to have face-to-face discussions, or you may choose written or audio materials, or a combination. You may prefer to be given a lot of information to read and think about right from the start, or you may prefer to be given information more gradually, as your treatment progresses. You should feel confident that you understand the information you have been given. You should be given the opportunity to discuss any problems and to ask questions. Always ask if there is something you do not understand or if you would like more information.

Your healthcare team should also talk with you about how much you want to be involved in making decisions. Decisions about treatments can involve having to think about complex issues, such as considering possible unpleasant side effects and possible benefits, and thinking about your family, your cultural and religious beliefs and your social circumstances. Your healthcare team should give you the information, time and support you need, and they should keep on talking with you and supporting you throughout your care.

Decision aids, such as tape recordings of consultations, lists of questions to ask, face to face counselling and interactive computer programmes can also be used to help people make decisions about their treatment if they wish to be involved. Your healthcare team should offer you more information about these.

Scans and tests

The treatments you might be offered depend on the type of cancer you have, how far it has spread, your general health, any previous cancer treatment you may have had, and your wishes.

You should be offered X-rays and scans to find out if the cancer has spread to other parts of your body.

You may be offered a biopsy to find out if your cancer is oestrogen receptor-positive and suitable for endocrine therapy (see page 8) or if it is HER2-positive and suitable for treatment with trastuzumab (Herceptin). For most people, this information will be known from the treatment they have previously had for early breast cancer.

Oestrogen receptor-positive breast cancer

Some breast cancers are affected by the female hormone oestrogen. These are known as oestrogen receptor-positive breast cancers, (sometimes shortened to ER-positive). This means that the breast cancer is more likely to grow when oestrogen is present. Endocrine therapy (see page 8) that blocks oestrogen or stops it being made can be used to stop the cancer growing.

HER2-positive breast cancer

About one cancer in five is HER2 positive, which means that the cancer contains a protein called HER2 which helps it grow. HER2 stands for 'human epidermal growth factor receptor 2'. A drug called trastuzumab (Herceptin) can be used to treat HER2-positive breast cancer. It works by targeting the HER2 protein. It can only work for patients whose cancers have high levels of the HER2 protein, and unfortunately does not always work even for them. For more information, please see the 'Understanding NICE guidance' about trastuzumab for breast cancer (www.nice.org.uk/TA34).

Your healthcare team will discuss the results of your tests and your treatment options with you. These explanations can be complex and confusing. The box below includes some questions you might like to ask.

Questions you might like to ask your healthcare team

- Can I check that I've understood what you've said?
- Can you explain it again? I still don't understand.
- Is there a leaflet or other information that I can take home?
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?

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

Decisions about these treatments should be made between you and your healthcare team, and based on your understanding of the possible risks and benefits involved.

Treatment

If your cancer is oestrogen receptor-positive

NICE has said that when the cancer is imminently life-threatening and needs immediate treatment, chemotherapy (see page 10) should be offered, providing the patient understands the side effects and is well enough to cope with them. If this is the case (and chemotherapy is offered first), patients should be offered endocrine therapy when they have finished the chemotherapy.

If the cancer is not imminently life-threatening, patients should first be offered endocrine therapy (see box below) to slow the growth of the cancer or cause it to shrink.

If your cancer is growing and causing symptoms despite endocrine therapy, then you may be offered treatment with chemotherapy.

Endocrine therapy

Aromatase inhibitor

What is it?

A type of drug that targets a substance in the body called aromatase that helps make oestrogen.

How does it work?

It reduces the levels of oestrogen in women who have been through the menopause.

Who is it suitable for?

Women with oestrogen receptor-positive advanced breast cancer who have been through the menopause; if they have not already had endocrine therapy, or if tamoxifen has not stopped the cancer from growing.

Tamoxifen together with ovarian suppression

What is it?

Tamoxifen is an anticancer drug that blocks the effects of oestrogen. Ovarian suppression is drug treatment, surgery or radiotherapy which stops the ovaries producing oestrogen.

How does it work?

Tamoxifen blocks oestrogen from binding to oestrogen receptor-positive cancer cells and stops the cancer from growing, while ovarian suppression stops the production of oestrogen from the ovaries.

Who is it suitable for?

Women with oestrogen receptor-positive advanced breast cancer who have not been through the menopause, and who have not already tried tamoxifen.

Ovarian suppression

What is it?

This may be drug treatment, surgery or radiotherapy to stop the ovaries from working and producing oestrogen.

How does it work?

Drug treatment (with a type of drug called a 'luteinising hormone-releasing hormone agonist', often shortened to 'LHRHa') temporarily stops the ovaries working, causing a woman's periods to stop. Unless she is very close to the menopause, the woman's ovaries may start to work again and her periods may return a few months after treatment is finished. Surgery to remove the ovaries and radiotherapy cause the ovaries to stop working permanently, which means that the menopause starts.

Who is it suitable for?

Women with oestrogen receptor-positive advanced breast cancer who have not yet been through the menopause, if previous treatment with tamoxifen has not stopped the cancer from growing.

Tamoxifen

What is it?

An anticancer drug that blocks the effects of oestrogen.

How does it work?

It blocks oestrogen from binding to oestrogen receptor-positive cancer cells and stops the cancer from growing.

Who is it suitable for?

Men with oestrogen receptor-positive advanced breast cancer and, when combined with ovarian suppression, women with oestrogen receptor-positive advanced breast cancer who have not been through the menopause, and who have not already tried tamoxifen.

Decisions about these treatments should be made between you and your healthcare team, and based on your understanding of the possible risks and benefits involved.

Chemotherapy

What is it?

Chemotherapy is the use of anticancer drugs that are given as tablets or intravenously (by injection into a vein using a 'drip'). Chemotherapy can cause many side effects and although it is offered to many patients with advanced breast cancer it will not be suitable for everyone. Sometimes patients may choose not to receive chemotherapy even if they are offered it and the healthcare team should support them in this decision, continuing treatment with supportive and palliative care.

There are different types of chemotherapy which work in different ways. NICE has recommended that most patients be treated with one type of chemotherapy at a time, and if the patient is no longer benefiting from it, another type of treatment may be considered.

What are the different types of drugs and who are they suitable for?

Anthracyclines

Anthracyclines are suitable for patients with advanced breast cancer if their healthcare team thinks they are well enough to cope with the side effects, and if they understand and accept the likely side effects.

Anthracyclines are not usually suitable for patients who have had anthracycline chemotherapy before.

Taxanes

The taxanes most often used to treat advanced breast cancer are docetaxel (also known as Taxotere) and paclitaxel (also known as Taxol). Both can be used with other chemotherapy drugs.

They are suitable for patients with advanced breast cancer who have already tried anthracyclines or if their healthcare team thinks that anthracyclines are not right for them. In most cases, docetaxel is chosen.

Gemcitabine (also known as Gemzar)

Gemcitabine can be used to treat patients with advanced breast cancer when it is combined with paclitaxel, if the patient has already tried anthracyclines or if their healthcare team thinks anthracyclines are not right for them. NICE has produced 'Understanding NICE guidance' about gemcitabine. See www.nice.org.uk/TA116

Vinorelbine (also known as Navelbine) and capecitabine (also known as Xeloda)

Vinorelbine and capecitabine are suitable for patients with advanced breast cancer who have tried anthracyclines and docetaxel, or if their healthcare team thinks that they are not right for them. Either vinorelbine or capecitabine should be offered. If one does not work, the other should be offered.

If your cancer is HER2-positive

If your cancer is HER2-positive, you may be offered a biological therapy called trastuzumab (Herceptin). NICE has produced 'Understanding NICE guidance' about trastuzumab for breast cancer. See www.nice.org.uk/TA34

Trastuzumab treatment should be stopped if the cancer starts to grow again, unless the cancer is **only** growing in the brain. Trastuzumab cannot get into the brain as effectively as it can get to other parts of the body. This means that if the cancer is only growing in the brain (and not anywhere else in the body), then other treatments such as surgery or radiotherapy should be used to treat the cancer in the brain, and trastuzumab should be continued to treat the cancer in the other parts of the body.

Decisions about these treatments should be made between you and your healthcare team, and based on your understanding of the possible risks and benefits involved.

Biological therapy

Trastuzumab

What is it?

Trastuzumab (also known as Herceptin) is a type of drug called a monoclonal antibody, which is used to treat patients with HER2-positive breast cancer.

How does it work?

It targets the HER2 protein to stop the cancer from growing.

Who is it suitable for?

Patients with HER2-positive breast cancer. It can only work for patients whose cancers have high levels of the HER2 protein, and unfortunately does not always work even for them. For more information, please see the 'Understanding NICE guidance' about trastuzumab for breast cancer (www.nice.org.uk/TA34).

Questions you may wish to ask

- Please tell me why you have decided to offer me this particular type of treatment.
- Do I have to have this treatment?
- What will happen if I choose to have no further treatment?
- What are the pros and cons of having this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- How will I know it has worked?
- Can you tell me about the risks of having this treatment?
- What are my options for having treatments other than the recommended treatment?
- Is there some written material (like a leaflet) about the treatment that I can have?

Complications

You may require additional treatment if the cancer spreads to your bones or your brain, or if other complications occur.

| Complication | What is it? | How will it affect me? | What can be done about it? |
|----------------------------|--|---|--|
| Lymphoedema | A build up of excess fluids. In breast cancer this usually affects the arm. It can happen at any time after cancer surgery or it can sometimes happen when cancer is present under the arm in patients with advanced breast cancer. | You may experience discomfort or pain that can persist for months or years after cancer treatment. The skin on your arm may feel dry and tight, and your arm may feel heavy. You may not be able to move it properly or to lift it very high. | Your healthcare team should first assess whether your lymphoedema is caused by factors that may be treatable. You should be offered treatment and special bandaging to reduce the swelling in the arm. Your healthcare team should provide you with at least two compression garments that are tailored to your needs and preferences. You should be given information on lymphoedema and the details of local and national support groups. |
| Cancer-related fatigue | Fatigue is the most common side effect of chemotherapy. It occurs in up to 9 out of 10 breast cancer patients, and in nearly half breast cancer patients who have finished treatment. Unlike normal tiredness, rest does not usually resolve cancer-related fatigue. | You may feel constantly as though you have no energy and are tired. You may lose interest in things you would normally enjoy. | You should be offered an assessment to try to find out whether there are any reversible causes for your fatigue which can easily be treated. You should be given information on cancer-related fatigue and details of organisations and patient-led groups. You should be given information about and the chance to take part in an exercise programme. |
| Uncontrolled local disease | When the tumour in the breast is not completely destroyed by treatment and causes more damage to the area | You may develop painful ulcers on the surface of the breast that require treatment. | Your healthcare team should talk to you about the treatment choices for controlling the disease, relieving symptoms and also how they can provide psychological support and help with coping. Wound care specialists and palliative care specialists should be part of the team responsible for treating uncontrolled local disease. |
| Bone metastases | When the cancer spreads to the bones. | Your bones may be at higher risk of fracturing or breaking and you may experience pain. | You may be offered drugs called bisphosphonates to strengthen your bones. You should be offered radiotherapy if you are in pain that does not get better with other treatments. If you are at risk of breaking an arm or leg, you should be assessed by an orthopaedic surgeon. |
| Brain metastases | When the cancer spreads to the brain. | You may have headaches, notice changes in your speech, memory and movements. | You should be offered surgery followed by radiotherapy if your healthcare team thinks that surgery is appropriate. If surgery is not considered appropriate, you may be offered radiotherapy alone. You should be offered rehabilitation if you choose to have surgery and/or radiotherapy. If the brain cancer is unlikely to respond to treatment, you should be referred to a specialist palliative care service. |

More information

If you need further information and help about breast cancer, your feelings, anything that is worrying you, or the care that you are receiving, please ask your doctor, nurse or a member of your healthcare team. You can discuss this guideline with them if you wish, especially if you aren't sure about anything in this booklet. They will be able to explain things to you.

The organisations below can also provide more information and support for people with advanced breast cancer. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Breakthrough Breast Cancer, 08080 100 200
www.breakthrough.org.uk
- Breast Cancer Care, 0808 800 6000
www.breastcancercare.org.uk
- Lymphoedema Support Network, 020 7351 4480
www.lymphoedema.org/ltn
- Macmillan Cancer Support, 0808 808 2020
www.macmillan.org.uk
- Marie Curie Cancer Care, 020 7599 7777
www.mariecurie.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 also be able to give you further information and support.

For details of all NICE guidance on breast cancer and its treatments (both medical and surgical), visit our website at www.nice.org.uk/Guidance/Topic

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider 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 this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG81. The versions for healthcare professionals contain more detailed information on the care and treatment you should be offered.

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1795).

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