INFLAMMATORY BREAST CANCER

BREAST CANCER NOW The research & support charity

About this booklet

It's normal to have lots of questions if you've been diagnosed with inflammatory breast cancer.

This booklet explains what inflammatory breast cancer is, the symptoms, how it's diagnosed and how it may be treated.

We hope this booklet helps you to ask your treatment team questions and be as involved as you want in decisions about your treatment.

You may like to read it alongside our booklets **Treating primary** breast cancer and **Diagnosed with breast cancer: what now?**

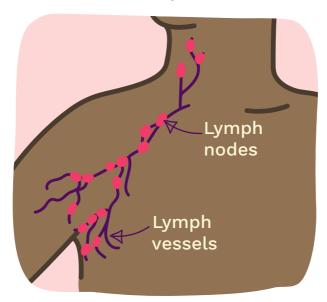
What is inflammatory breast cancer?

Inflammatory breast cancer is a rare, fast-growing type of breast cancer.

It's called inflammatory because the skin of the breast usually looks red and inflamed. This is caused by the breast cancer cells blocking the tiny lymph vessels (similar to blood vessels) in the breast and the skin.

The lymph vessels are part of the lymphatic system. The lymphatic system is made up of a network of lymph vessels connected to groups of lymph nodes found throughout the body.

The lymphatic system helps to maintain the balance of fluid in the tissues of the body by draining, filtering and transporting lymphatic fluid around the body.



In inflammatory breast cancer the cancer cells block the lymph vessels in the breast and skin, causing redness and swelling

Symptoms

The symptoms of inflammatory breast cancer can develop quickly.

Symptoms can include:

- · Redness, warmth or swelling of the breast
- The skin of the breast changing colour or looking bruised
- Ridges or thickening of the skin
- The skin looking dimpled or pitted like the skin of an orange (this is also known as peau d'orange)
- · An increase in breast size
- · Persistent itching of the breast
- An inverted (pulled-in) nipple
- Swelling or lumps in the armpit or around the collarbone
- Pain or tenderness in the breast

You may or may not have a lump.

How is inflammatory breast cancer diagnosed?

Inflammatory breast cancer is sometimes difficult to diagnose. This is because the symptoms are similar to some benign (not cancer) conditions such as a breast infection (mastitis) or a breast abscess. These are usually treated with antibiotics.

If you are prescribed antibiotics but your symptoms do not improve, your GP will refer you to a breast clinic.

At the breast clinic you may have several tests, including:

- Mammogram a breast x-ray
- Ultrasound scan uses sound waves to produce an image
- Breast MRI uses magnetism and radio waves to produce a series of images of the inside of the breast
- Biopsy removal of breast tissue to be looked at under a microscope
- Punch biopsy removal of breast tissue and a small circle of skin

For more information, see our **Your breast clinic appointment** booklet.

If you are diagnosed with inflammatory breast cancer, you may have further tests to check whether the cancer has spread outside the breast. These may include:

- PET (positron emission tomography) or CT (computerised tomography) scan, also known as a CAT scan – uses x-rays to take detailed pictures across the body
- Bone scan a test to help identify any abnormal changes, such as tumours, infection or fractures, in the bones

You may also have medical photographs taken of your breast to see how you respond to treatment.

If you need to have any of these tests, your treatment team will explain more about them. You can also call our free helpline on **0808 800 6000** to talk this through or to find out more information

How is inflammatory breast cancer treated?

Your treatment team will discuss your treatment options with you and prepare a treatment plan. The plan will be based on your test results.

Because inflammatory breast cancer can develop quickly, treatment is usually started as soon as possible.

Treatment usually involves treating the whole body with drugs (systemic treatment) as well as the affected breast and the area around it (local treatment).

Depending on your situation, you may have a combination of chemotherapy, surgery, radiotherapy, targeted therapy, hormone (endocrine) therapy and bisphosphonates.

Chemotherapy

Chemotherapy destroys cancer cells by affecting their ability to divide and grow.

It's given to treat and reduce the size of the cancer in the breast and to try to destroy any cancer cells that may have spread elsewhere in the body.

Chemotherapy is usually the first treatment recommended for inflammatory breast cancer, before any surgery. Because it's the first treatment recommended, it's called primary or neo-adjuvant chemotherapy.

For more information, see our **Chemotherapy for breast cancer** booklet.

Surgery

Most people will have surgery after chemotherapy.

Usually, the whole breast is removed, including the nipple area (mastectomy).

Your surgeon will normally remove the lymph nodes from under your arm (axilla) at the same time.

If you're able to have a breast reconstruction following a mastectomy, this is likely to be offered when you have completed all your treatment. This is called delayed breast reconstruction.

Radiotherapy

Radiotherapy uses high energy x-rays to destroy cancer cells. It's often used after chemotherapy and surgery to treat inflammatory breast cancer.

You will usually have treatment to the whole breast area.

Depending on your situation, you may be offered radiotherapy above your collarbone (clavicle), under your arm (axilla) and occasionally to the lymph nodes behind the breastbone (sternum).

For more information, see our **Radiotherapy for primary breast** cancer booklet.

Targeted therapy

Targeted therapy is the name given to a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that help cancer grow.

The type of targeted therapy you are given will depend on the features of your breast cancer.

The most widely used targeted therapies are for HER2-positive breast cancer. HER2 is a protein that helps cancer cells grow.

There are various tests to measure HER2 levels, which are done on breast tissue removed during a biopsy or surgery. Only people whose cancer has high levels of HER2 (HER2-positive) will benefit from this type of treatment.

Examples of targeted therapies for HER2-positive breast cancer include trastuzumab and pertuzumab.

If your cancer is HER2-negative, targeted therapies for HER2-positive breast cancer will not be of any benefit.

For more information, see our **Trastuzumab** and **Pertuzumab** (**Perjeta**) booklets and our webpages on other targeted therapies **breastcancernow.org/targeted-therapy**

Hormone (endocrine) therapy

Oestrogen receptor positive (ER-positive)

Some breast cancers use oestrogen in the body to help them grow. These are known as oestrogen receptor positive or ERpositive breast cancers.

Hormone therapies block or stop the effect of oestrogen on breast cancer cells. Different hormone therapy drugs do this in different ways.

You will only be prescribed hormone therapy if your breast cancer is ER-positive. Invasive breast cancers are tested to see if they are ER-positive using tissue from a biopsy or after surgery. If your cancer is ER-positive, your specialist will discuss which therapy they think is most appropriate.

For more information, see our **Treating primary breast cancer** booklet or our individual hormone drug booklets.

Pre-menopausal women with ER-positive breast cancer may also be offered ovarian suppression. Ovarian suppression is the term used to describe treatments that stop the ovaries from making oestrogen, either permanently or temporarily.

Oestrogen receptor negative (ER-negative)

If your breast cancer does not use oestrogen to help it grow, it's called oestrogen receptor negative (ER-negative).

You will not be prescribed hormone therapy if your breast cancer is ER-negative, as it will not be of any benefit.

Progesterone receptor positive (PR-positive)

You'll also have tests to see if a hormone called progesterone is helping your breast cancer grow. If it is, it's called progesterone receptor positive or PR-positive.

The benefits of hormone therapy are less clear for people whose breast cancer is PR-positive but ER-negative. Very few breast cancers fall into this category. But your specialist will discuss whether hormone therapy is appropriate if this is the case.

Bisphosphonates

Bisphosphonates are a group of drugs that can reduce the risk of breast cancer spreading in women who have been through the menopause. They can be used if the menopause happened naturally or because of breast cancer treatment.

Your treatment team can tell you if bisphosphonates would be suitable for you.

For more information, see our individual bisphosphonate drug booklet **Zoledronic acid for primary breast cancer**.

Bisphosphonates slow down or prevent loss of bone tissue.

They may also be prescribed:

- For people who are at risk of, or who have, osteoporosis (when bones lose their strength and are more likely to break)
- As treatment for secondary breast cancer in the bone (when cancer that started in the breast has spread to the bones)

Clinical trials

Clinical trials are research studies that aim to improve treatment or care for patients. Studies into treatments for inflammatory breast cancer are ongoing. This is something you can discuss with your treatment team, so you can decide what's best for you.

There is general information available on clinical trials on our website **breastcancernow.org**, or you can visit cancerresearch.org.uk for listings of current UK trials.

Follow-up

At the end of your hospital-based treatment, you will continue to be monitored. This is known as follow-up.

How you are followed up will depend on your individual needs and on the arrangements at the hospital where you were treated. You'll probably find your contact is more frequent at first, becoming less so as time goes on.

Your treatment team will give you a name and contact number you can use if you have any questions or concerns between your appointments. This is usually for a breast care nurse. You can also talk to your GP about any concerns you have.

For more information about follow-up, see our booklet After breast cancer treatment: what now?

Further support

Being diagnosed with inflammatory breast cancer can be a difficult and frightening time.

There are people who can support you, so don't be afraid to ask for help if you need it.

Some people find it helpful to discuss their feelings and concerns with their breast care nurse or specialist. If you'd like to talk through how you are feeling in more depth, you may want to see a counsellor or psychologist. Your breast care nurse, specialist or GP can arrange this.

You can also call our helpline on **0808 800 6000** and talk through your diagnosis, treatment and how you are feeling with one of our team.

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We're Breast Cancer Now, the research and support charity. However you're experiencing breast cancer, we're here.

Life-changing support

Whoever you are, and whatever your experience of breast cancer, our free services are here. Whether you're worried about breast cancer, dealing with a diagnosis, working out life with or beyond treatment – or someone you love is.

World-class research

We support over 290 of the brightest minds in breast cancer research. They're discovering how to prevent breast cancer, live well with the disease, and save lives. Every day, they get closer to the next breakthrough.

Change-making campaigns

We fight for the best possible treatment, services and care for everyone affected by breast cancer, alongside thousands of dedicated campaigners.

Could you help?

We don't get any government or NHS funding for our support services or health information. So, we rely on donations and gifts in wills to make our vital work happen. If you'd like to support us, go to breastcancernow.org/give

ABOUT THIS BOOKLET

Inflammatory breast cancer was written by Breast Cancer Now's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it: Email health-info@breastcancernow.org



You can order or download more copies from breastcancernow.org/publications



We welcome your feedback on this publication: health-info@breastcancernow.org



For a large print, Braille or audio CD version: Email health-info@breastcancernow.org

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Information you can trust, support you can count on

Whatever breast cancer brings, we're here for you.

Whether you're looking for information about breast cancer or want to speak to someone who understands, you can rely on us.

Call **0808 800 6000** to talk things through with our helpline nurses.

Visit **breastcancernow.org** for reliable breast cancer information.

Breast Cancer Now

6th Floor The White Chapel Building 10 Whitechapel High Street London E1 8QS



Patient Information Forum

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