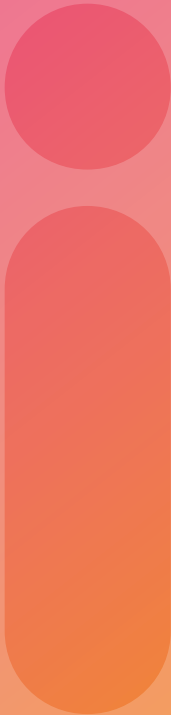


Invasive lobular breast cancer

breast
cancer
care

This booklet is about invasive lobular breast cancer. It describes what invasive lobular breast cancer is, the symptoms, how a diagnosis is made and possible treatments.



This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**



Introduction

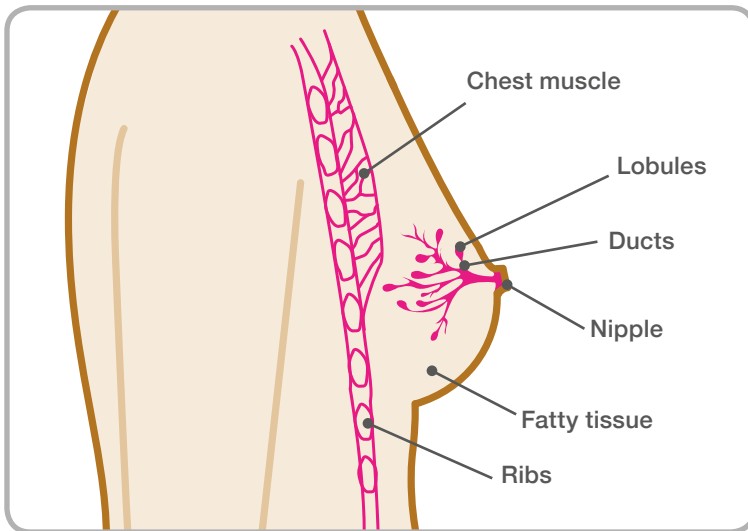
We hope this booklet helps you to ask your specialist team questions and be involved as much as you want in decisions about your treatment. We recommend reading it alongside our **Treating primary breast cancer** booklet.

What is invasive lobular breast cancer?

Invasive lobular breast cancer is a type of cancer that starts in the lobules (milk-producing glands) of the breast.

Breast cancer starts when cells in the breast begin to divide and grow in an abnormal way.

Invasive lobular breast cancer occurs when these abnormal cancer cells have started to grow within the lobules and then spread into the surrounding breast tissue.



Invasive lobular breast cancer accounts for up to 15% of all breast cancers. It can occur at any age but is most common in pre-menopausal women (women who have not been through the menopause). Men can also get invasive lobular breast cancer but this is very rare.

Sometimes invasive lobular breast cancer is found mixed with other types of breast cancer such as DCIS (ductal carcinoma in situ) or invasive ductal breast cancer. We have booklets on both these types of breast cancer.

What are the symptoms?

Invasive lobular breast cancer may not cause any obvious changes to the breast. You may notice an area that feels thicker or harder than the rest of the breast, rather than a definite lump. Other possible symptoms can include changes in skin texture such as puckering or dimpling (like the skin of an orange), or the nipple becoming pulled in.

In some women it is found during routine breast screening before any symptoms are noticed, but lobular breast cancer can be more difficult to see on a mammogram than other types of breast cancer.

How is it diagnosed?

Invasive lobular breast cancer can be difficult to diagnose if there are no obvious symptoms.

When you visit the breast clinic you will have a breast examination, usually followed by a mammogram (breast x-ray). As well as a mammogram you'll probably have an ultrasound scan of the breast and the axilla (under the arm). An ultrasound scan uses high frequency sound waves to produce an image.

A small sample of breast cells or breast tissue may be taken from the breast to help make a diagnosis. This will most commonly be done using a core biopsy. A core biopsy uses a hollow needle to take a sample of breast tissue. Sometimes a fine needle aspiration (FNA) may be used. This uses a fine needle and syringe to take a sample of cells. The sample is then sent to the laboratory where it is looked at under a microscope.

Invasive lobular breast cancer can sometimes be more difficult than other types of breast cancer to locate and measure using an ultrasound or mammogram, so you may have a magnetic resonance imaging (MRI) scan. An MRI scan uses magnetic fields and radio waves to produce a series of images of the inside of the breast. It can sometimes provide a

more accurate picture of the size of this type of cancer, and whether it affects more than one area in the breast. Both breasts will be checked.

If you'd like more information about these tests see our booklet **Your breast clinic appointment**.

Sometimes more than one area of invasive lobular cancer is found in the same breast.

How is it treated?

Surgery

Surgery is usually the first treatment for invasive lobular breast cancer.

The type of surgery recommended will depend on the area of the breast affected, the size of the cancer compared to the size of your breast, and whether more than one area in the breast is affected.

Breast-conserving surgery

Breast-conserving surgery, also known as wide local excision or lumpectomy, is the removal of the cancer with a margin (border) of normal breast tissue around it.

If breast-conserving surgery is being considered, an MRI scan may be recommended to assess the size of the cancer (if you haven't already had one to confirm the diagnosis). Your breast surgeon will discuss this with you.

Even after an MRI scan, it can sometimes be difficult to estimate the size of an invasive lobular breast cancer before surgery. Because of this, some women who have breast-conserving surgery may need a second operation. This is to ensure all the cancer, and a margin of normal breast tissue around it, has been removed. In some cases, a mastectomy will be recommended as the second operation.

Mastectomy

A mastectomy is the removal of all the breast tissue and nipple area.

Invasive lobular breast cancer can affect more than one area in the breast. If this is the case the breast surgeon may recommend a mastectomy, but this will depend on the position of the areas affected and the size of your breast.

If a mastectomy is recommended, or if you choose to have a mastectomy, you will usually be able to have breast reconstruction. This can be done at the same time as your mastectomy (immediate reconstruction) or sometime in the future (delayed reconstruction). If you'd like more information see our **Breast reconstruction** booklet.

Surgery to the lymph nodes

Your doctors will also want to check whether breast cancer cells have spread from the breast to the lymph nodes (glands) under the arm (axilla). This will help them decide whether you will need additional treatment after surgery. To do this, your surgeon is likely to recommend an operation to remove either some of the lymph nodes (a lymph node sample or biopsy) or all of them (a lymph node clearance).

Sentinel lymph node biopsy is widely used if tests before surgery show no evidence of the lymph nodes containing cancer cells. It identifies whether the first lymph node (or nodes) is clear of cancer cells. If it is, this usually means the other nodes are also clear, so no more will need to be removed.

If the results of the sentinel lymph node biopsy show that the first node or nodes are affected you may be recommended to have further surgery or radiotherapy to the remaining lymph nodes.

Sentinel lymph node biopsy is not suitable if tests before your operation show that your lymph nodes contain cancer cells. In this case it is likely that your surgeon will recommend a lymph node clearance.

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

What are the adjuvant (additional) treatments?

After surgery you may need further treatment. This is called adjuvant (additional) therapy and includes radiotherapy, hormone therapy, chemotherapy and targeted therapy. Which treatment you have will depend on your individual situation.

The aim of these treatments is to reduce the risk of breast cancer cells returning in the same breast or developing in the other breast, or spreading somewhere else in the body.

Sometimes chemotherapy or hormone therapy may be given before surgery. This is known as neo-adjuvant or primary therapy.

Radiotherapy

Radiotherapy uses high energy x-rays to destroy cancer cells.

If you have breast-conserving surgery you will usually be given radiotherapy to reduce the risk of the breast cancer returning in the same breast (known as recurrence). Sometimes you may be offered radiotherapy to the nodes under your arm.

If you have a mastectomy you may be given radiotherapy to the chest in the area where you had your surgery. This is more likely if the tumour was large, if there is a high risk that cancer cells may have been left behind or if cancer cells are found in the lymph nodes under the arm. For more information about radiotherapy see our **Radiotherapy for primary breast cancer** booklet.

Hormone (endocrine) therapy

The hormone oestrogen can stimulate some breast cancers to grow. A number of hormone therapies work in different ways to block the effect of oestrogen on cancer cells.

Hormone therapy will only be prescribed if your breast cancer has receptors within the cell that bind to the hormone oestrogen, known as oestrogen receptor positive or ER+ breast cancer.

Invasive breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery. When oestrogen binds to these receptors, it can stimulate the cancer to grow.

Most invasive lobular cancers are oestrogen receptor positive. If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

If oestrogen receptors are not found it is known as oestrogen receptor negative or ER-.

Sometimes tests may be done for progesterone (another hormone) receptors. The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case for you your specialist will discuss with you whether hormone therapy is appropriate.

If your cancer is hormone receptor negative, then hormone therapy will not be of any benefit.

See our **Treating primary breast cancer** booklet or our individual hormone drug booklets for more information.

Chemotherapy

Chemotherapy destroys cancer cells using anti-cancer drugs.

Chemotherapy is recommended for some people. This will depend on various features of the cancer, such as its size, its grade (how different the cells are to normal breast cells and how quickly they are growing) and whether the lymph nodes are affected. If you'd like more information see our **Chemotherapy for breast cancer** booklet.

Targeted therapy

This is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

The most widely used targeted therapy is trastuzumab (Herceptin). Only people whose cancer has high levels of HER2 (called HER2 positive) will benefit from having trastuzumab. HER2 is a protein that makes cancer cells grow. Most invasive lobular breast cancers are HER2 negative.

There are various tests to measure HER2 levels, which are done on breast tissue removed by biopsy or during surgery. If your cancer is found to be HER2 negative, then trastuzumab will not help you.

Follow-up after treatment

You will continue to be monitored after your hospital-based treatments (such as surgery, chemotherapy or radiotherapy) finish. This is known as follow-up. If you had breast-conserving surgery, follow-up will include regular mammograms to both breasts. If you had a mastectomy, a mammogram will be carried out on your untreated breast.

If your invasive lobular breast cancer wasn't originally seen on a mammogram, you may be concerned that follow-up mammograms won't be effective in detecting changes in your breast. However, mammograms are still useful in picking up early changes.

Whether you've had breast-conserving surgery or a mastectomy (with or without reconstruction), it's also important to be aware of any changes to the breast, chest or surrounding area. After treatment for breast cancer it can be difficult to know how your breast or scar area should feel. The area around the scar may feel lumpy, numb or sensitive. This means that you will need to get to know how it looks and feels so you know what's normal for you. This will help you to feel more confident about noticing changes and reporting them early to your GP (local doctor) or breast care nurse.

It's also important to be aware of any new changes in the other breast and to report these as soon as possible.

Having breast cancer in one breast means the risk of developing cancer in the other breast (a new primary breast cancer) is slightly higher than in someone who's never had breast cancer. With invasive lobular breast cancer, this risk may be slightly higher than with other types of breast cancer, but it's still very low overall.

For more information, see our booklet **After breast cancer treatment: what now?** If you have any concerns you can speak with your GP or breast care nurse.

Further support

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

There may be times when you feel alone or isolated. 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 your feelings and concerns in more depth over a period of time, you may want to see a counsellor or psychologist. Your breast care nurse, specialist or GP can arrange this.

You can also call Breast Cancer Care's Helpline on **0808 800 6000** and talk through your diagnosis, treatment and how you are feeling with one of our team.



4 ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone who knows what it's like or want to read more about breast cancer, here's how you can.



Speak to trained experts, nurses or someone who's had breast cancer and been in your shoes. Call free on **0808 800 6000** (Monday to Friday 9am–5pm, Wednesdays til 7pm and Saturday 9am–1pm).



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at forum.breastcancercare.org.uk



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at breastcancercare.org.uk



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you. Visit breastcancercare.org.uk/in-your-area

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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Please accept my donation of **£10/£20/my own choice of £**

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We might occasionally want to send you more information about our services and activities

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Chester House, 1-3 Brixton Road, London SW9 6DE



About this booklet

Invasive lobular breast cancer was written by Breast Cancer Care'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:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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