

Invasive lobular breast cancer

This booklet is about invasive lobular breast cancer. It describes what invasive lobular breast cancer is, the symptoms, how it's diagnosed and possible treatments.

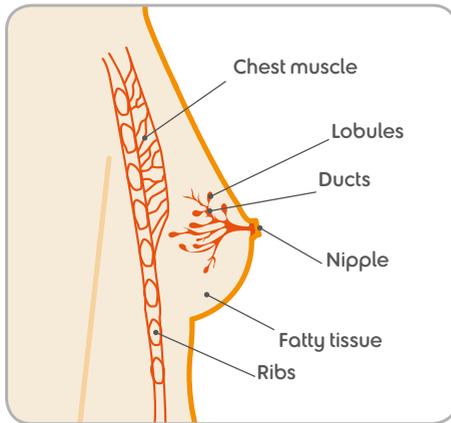
Introduction

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 breast cancer** booklet.

What is invasive lobular breast cancer?

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 (milk-producing glands) and then spread into the surrounding breast tissue.

The breast



Invasive lobular breast cancer accounts for up to 15% of all breast cancers. It can occur at any age but is most common in women who have been through the menopause. Men can also get invasive lobular breast cancer but this is very rare.

What are the symptoms?

Invasive lobular breast cancer may not cause any obvious changes to the breast. You may notice a hardened or thickened area of breast tissue rather than a definite lump. Other changes may also occur in the breast, such as dimpling or flattening of an area, or the nipple turning inward.

How is it diagnosed?

Invasive lobular breast cancer can be difficult to diagnose if there are no obvious symptoms. In some women it is found during routine breast screening before any symptoms are noticed.

If you have been referred to a breast clinic, your breasts (including the area under your arms and up around the collar bone) will be examined by a doctor or specialist nurse. You will then usually have a mammogram (breast x-ray). However, some invasive lobular breast cancers can be difficult to see on a mammogram.

As well as a mammogram you'll probably have an ultrasound scan of the breast and the axilla (under the arm), a core biopsy and possibly a fine needle aspiration (FNA).

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

Invasive lobular breast cancer can sometimes be more difficult than other types of breast cancer to identify and measure using an ultrasound or mammogram, so you may have a magnetic resonance imaging (MRI) scan. An MRI 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.

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

Having breast cancer in one breast means the risk of developing cancer in the other breast 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.

What are the treatments?

Surgery

Surgery is usually the first treatment for invasive lobular breast cancer. This may be breast-conserving surgery (the removal of the cancer and an area of normal breast tissue around the cancer) or a mastectomy (the removal of all the breast tissue and nipple area).

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.

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 (border) of normal breast tissue around it, has been removed. In some cases, a mastectomy will be recommended as the second operation.

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. 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 (a lymph node sample or biopsy) or all of the lymph nodes (a lymph node clearance).

A widely used method for checking these lymph nodes is called sentinel lymph node biopsy. This checks 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) is affected you may be recommended to have further surgery or radiotherapy to the remaining lymph nodes.

Sentinel lymph node biopsy is not suitable for everyone, and your surgeon will discuss whether it's an option for you.

If tests before your operation show that your lymph nodes contain cancer cells, then your surgeon will probably recommend removal of all the lymph nodes rather than a sentinel lymph node biopsy.

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

What are the adjuvant (additional) treatments?

After surgery you may need further treatment. This is called adjuvant (additional) therapy and includes chemotherapy, radiotherapy, hormone therapy and targeted therapies. 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.

Chemotherapy

Chemotherapy is recommended for some people. This will depend on various features of the cancer, such as its size, its grade (how quickly the cells are dividing and how different they are to normal breast cells) and whether the lymph nodes are affected.

If you'd like more information see our **Chemotherapy for breast cancer** booklet.

Radiotherapy

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. 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 may be the case 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 (axilla).

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

Hormone (endocrine) therapy

As the hormone oestrogen can play a part in stimulating some breast cancers to grow, there are a number of hormone therapies that 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). All 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. If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

Most invasive lobular cancers are oestrogen receptor positive, which means that your doctors may recommend you have hormone therapy.

When oestrogen receptors are not found (oestrogen receptor negative or ER-) tests may be done for progesterone (another hormone) receptors. As oestrogen receptors play a more important role than progesterone 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 whether hormone therapy is appropriate.

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

If you would like more information, see our **Treating breast cancer** booklet or our individual hormone drug booklets.

Targeted therapies

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 (HER2 positive or HER2+), a protein that makes cancer cells grow, will benefit from having trastuzumab. 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

At the end of your hospital-based treatment, your specialist team will continue to have contact with you to check how you're recovering. 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 unaffected 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.

It's also important to be aware of any changes in the breast or chest area. After treatment for breast cancer it can be difficult to know how your breast or chest and 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 hospital team.

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

For more information, see our booklet **Your follow-up after breast cancer**.

If you have any concerns you can speak with your surgeon or breast care nurse (if you have one).

Coping with breast cancer

Being diagnosed with breast cancer can be a difficult and frightening time. Everyone reacts differently to their diagnosis and has their own way of coping.

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. By letting other people know how you feel, particularly your family and friends, they can be more supportive.

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, a counsellor or psychologist may be more appropriate. Your breast care nurse, specialist or GP can arrange this.

If you have any questions or want to talk you can call our Helpline on **0808 800 6000**.

Helping you face breast cancer

If you've been diagnosed with breast cancer there's a lot to take in. It can be an emotional time for you, your family and friends. Our free information and support services are here to help – on the phone, or online 24 hours a day.

Ask us

Calls to our free Helpline are answered by specialist nurses and trained staff with personal experience of breast cancer. They'll understand the issues you're facing and can answer your questions. Or you can Ask the Nurse by email instead via our website.

Free Helpline **0808 800 6000** (Text Relay 18001)
Monday–Friday 9am–5pm, Saturday 10am–2pm
www.breastcancercare.org.uk/ATN

Expert information

Written and reviewed by healthcare professionals and people affected by breast cancer, our free booklets and other information resources cover all aspects of living with breast cancer. Download or order booklets from our website or call the Helpline.

Talk to someone who understands

Our Someone Like Me service puts you in contact with someone else who's had breast cancer and who's been fully trained to help. This can be over the phone or by email.

You can also chat to other people going through breast cancer on our online discussion Forum. It's easy to use, professionally moderated and available to read any time of day.

Find out more about all of our services for people with breast cancer at www.breastcancercare.org.uk/services or phone the Helpline.

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

- Please tick if you're happy to receive email from us
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We won't pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG,
5-13 Great Suffolk Street, London SE1 0NS



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:**

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the breast cancer
support charity

Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer.

Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.

Visit www.breastcancercare.org.uk or call us free on **0808 800 6000** (Text Relay 18001).

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Diagnosed with breast cancer