

INVASIVE LOBULAR BREAST CANCER



BREAST
CANCER
NOW

The research &
support charity

2 Call our Helpline on **0808 800 6000**

About this booklet

It's normal to have lots of questions about invasive lobular breast cancer, whether you've been diagnosed with it or are close to someone who has.

This booklet explains what invasive lobular breast cancer is, what the symptoms are, and what treatment might look like.

You may also find it useful to read our **Treating primary breast cancer** booklet.

What is invasive lobular breast cancer?

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

“Invasive” means the cancer cells have spread outside the lobules into the surrounding breast tissue.

You may also hear it called invasive lobular carcinoma of the breast or ILC.

Around 15 in every 100 breast cancers are invasive lobular breast cancer.

Women can develop invasive lobular breast cancer at any age but it's more common as they get older. 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 ductal carcinoma in situ (DCIS) or invasive ductal breast cancer. We have booklets on both these types of breast cancer.

Symptoms of invasive lobular breast cancer

Symptoms of invasive lobular breast cancer include:

- A thickening of the breast tissue
- A change in the shape or size of the breast
- A change of skin texture such as puckering or dimpling
- A lump or swelling under the arm
- Changes to the nipple
- Discharge from the nipple
- A breast lump (although this is less common)

Invasive lobular breast cancer may not cause any obvious changes to the breast.

You may be diagnosed with invasive lobular breast cancer during routine breast screening before you have noticed any symptoms. However, lobular breast cancer can be more difficult to see on a mammogram than other types of breast cancer.

Diagnosing invasive lobular breast cancer

Invasive lobular breast cancer is diagnosed using a range of tests, which may include:

- A mammogram (breast x-ray)
- An ultrasound scan (using sound waves to produce an image)
- A core biopsy of the breast and sometimes lymph nodes (using a hollow needle to take a sample of tissue to be looked at under a microscope – several tissue samples may be taken at the same time)
- A fine needle aspiration (FNA) of the breast and sometimes lymph nodes (using a needle and syringe to take a sample of cells to be looked at under a microscope)
- A breast MRI (using magnetism and radio waves to produce a series of images of the inside of the body)

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See our booklet **Your breast clinic appointment** for more information about these tests and what to expect at your breast clinic appointment.

Sometimes more than 1 area of invasive lobular breast cancer is found in the same breast.

Invasive lobular breast cancer can also sometimes be found in both breasts (bilateral).

Treatment

Surgery

The first treatment for invasive lobular breast cancer is usually surgery.

The type of surgery your surgeon recommends will depend on factors such as:

- Where the cancer is in the breast
- The size of the cancer in relation to the size of your breast
- Whether more than 1 area in the breast is affected

Types of breast surgery

You may have:

- Breast-conserving surgery: removal of the cancer with a margin (border) of normal breast tissue around it, also called wide local excision or lumpectomy
- A mastectomy: removal of all the breast tissue, usually including the nipple area

You can talk through your options with your treatment team.

Breast-conserving surgery

If you're having breast-conserving surgery, your specialist will let you know whether you need a breast MRI before the surgery. This is to look at the size of the cancer and whether there are any other areas of cancer within the breast.

However, a breast MRI does not always give an accurate estimate of the size of invasive lobular breast cancer. Because of this, some people who have breast-conserving surgery may need a second operation to make sure 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

If you are going to have a mastectomy, you will usually be offered breast reconstruction. This can be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction). If you would like more information, see our **Breast reconstruction** booklet.

If you have a mastectomy without breast reconstruction you may choose to wear a prosthesis (an artificial breast form that fits inside the bra). For more information on the options available, see our booklet **Breast prostheses, bras and clothes after surgery**.

Some people choose not to have reconstruction and not to wear a prosthesis after their mastectomy.

Surgery to the lymph nodes under the arm

Your treatment team will want to check if any cancer cells have spread to the lymph nodes (glands) under your arm.

Along with other information about your breast cancer, this helps them decide whether you'll benefit from any other treatment after surgery.

Sentinel lymph node biopsy

You may have a sentinel lymph node biopsy. The sentinel lymph node is the first lymph node cancer cells are likely to spread to. There may be more than one sentinel lymph node.

The procedure is usually done at the same time as your cancer surgery but may be done before.

If the results show the sentinel lymph node is clear of cancer cells, the other nodes are usually clear too, and no more will need to be removed.

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If the results show the first node or nodes contain cancer cells, you may be offered more surgery or radiotherapy to the remaining lymph nodes.

Sentinel lymph node biopsy is often done if tests before your surgery show no evidence the lymph nodes contain cancer cells.

Lymph node clearance

If tests before your operation show your lymph nodes contain cancer cells, your surgeon is likely to recommend an axillary lymph node clearance. This is when all the lymph nodes under the arm (axilla) are removed.

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

Other treatments

After surgery, you will usually need other treatments. These can include:

- Chemotherapy
- Radiotherapy
- Hormone (endocrine) therapy
- Targeted therapy
- Bisphosphonates

These treatments aim to reduce the risk of breast cancer returning in the same breast or spreading somewhere else in the body. Which treatments are recommended will depend on your individual situation.

Treatments given after surgery are called adjuvant treatments.

You may have some of these treatments before surgery. This is known as neo-adjuvant or primary therapy.

Chemotherapy

Chemotherapy destroys cancer cells by affecting their ability to divide and grow. It's given to reduce the risk of breast cancer returning or spreading.

Whether chemotherapy is recommended will depend on various features of the cancer, such as its:

- Size
- Grade
- Oestrogen receptor status (whether it uses oestrogen to help it grow)
- HER2 status (whether it uses the HER2 protein to help it grow)

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

Radiotherapy

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

If you have breast-conserving surgery, you will usually be offered radiotherapy to the breast. This is to reduce the risk of the cancer coming back in the same breast. You may also have radiotherapy to the lymph nodes under the arm or above the collar bone.

Radiotherapy is sometimes given to the chest wall after a mastectomy, for example if cancer cells have spread to the lymph nodes under the arm.

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

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 ER-positive breast cancers.

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

Hormone therapy will only be prescribed if your breast cancer is ER-positive.

Breast cancers are tested to see if they are ER-positive using tissue from a biopsy or after surgery.

Most invasive lobular breast cancers are ER-positive.

If your cancer is ER-positive, your specialist will talk to you about which hormone therapy they think is most appropriate.

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

Oestrogen receptor negative (ER-negative)

If oestrogen is not helping your breast cancer grow, it's ER-negative and hormone therapy will not be of 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 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 with you whether hormone therapy is appropriate if this is the case.

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 help cancer grow.

Whether you have targeted therapy, and the type of targeted therapy you may have, will depend on the features of your breast cancer.

For information about different types of targeted therapies, see breastcancernow.org/targeted-therapy

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.

Bisphosphonates can also slow down or prevent bone damage. They are often given to people who have, or are at risk of, osteoporosis (when bones lose their strength and are more likely to break).

Bisphosphonates can be given as a tablet or into a vein (intravenously).

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

For more information on bisphosphonates, see breastcancernow.org/bisphosphonates

After treatment

Follow-up

Your treatment team will continue to monitor you 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, you will have a mammogram on your untreated breast.

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

It's not currently standard practice to have a follow-up breast MRI scan for breast cancer. However, you can talk to your treatment team about your follow-up, as an MRI may sometimes be considered on a case-by-case basis.

Checking for changes

It's important to be aware of any changes to your breast, chest or surrounding area, whether you had breast-conserving surgery or a mastectomy (with or without reconstruction).

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 you will need to get to know how it looks and feels so you know what is normal for you. This will help you to feel more confident about noticing changes and reporting them early to your GP or breast care nurse.

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 has never had breast cancer. Therefore, it's important to be aware of any new changes in your other breast and to report these as soon as possible.

For more information, see our booklet **After breast cancer treatment: what now?**

If you have any concerns, speak with your GP or breast care nurse.

Secondary invasive lobular breast cancer

Secondary breast cancer occurs when the breast cancer cells spread from the primary (first) cancer in the breast to other parts of the body.

Secondary invasive lobular breast cancer can affect the:

- Digestive organs (stomach and intestine)
- Reproductive organs (uterus and ovaries)
- Lungs
- Liver
- Bones
- Brain
- Skin

It's important to be aware of the signs and symptoms of secondary breast cancer. You can find these on our webpage breastcancernow.org/secondary-symptoms

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Further support

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

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, you may want to see a counsellor or psychologist. Your breast care nurse, specialist or GP can arrange this.

Lobular Breast Cancer UK (lobularbreastcancer.org.uk) is a charity which shares personal stories of people diagnosed with lobular breast cancer and campaigns for better information and research into lobular breast cancer.

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.

NOTES

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

Invasive lobular 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:
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BREAST CANCER NOW

The research &
support charity

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

Fifth Floor
Ibex House
42–47 Minories
London EC3N 1DY



Patient Information Forum

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