INVASIVE LOBULAR BREAST CANCER

BREAST CANCER NOW The research & care charity

THIS INFORMATION IS BY BREAST CANCER NOW.

Steered by our world-class research and powered by our life-changing care, Breast Cancer Now is here for anyone affected by breast cancer, the whole way through, providing support for today and hope for the future.

Our breast care nurses, expertly trained staff and volunteers, and award-winning information is all here to make sure anyone diagnosed with breast cancer gets the support they need to help them to live well with the physical and emotional impact of the disease.

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

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ABOUT THIS BOOKLET

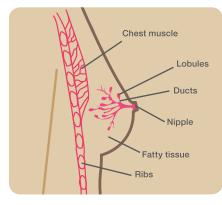
This booklet is about invasive lobular breast cancer, which is also known as invasive lobular carcinoma of the breast (ILC). We hope this information helps you discuss any questions you have with your treatment team. You may also find it useful to read our **Treating primary breast cancer** booklet.

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

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



Invasive lobular breast cancer accounts for up to 15 per cent of all breast cancers. It can occur at any age but is more common as women 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.

WHAT ARE THE SYMPTOMS?

Symptoms of invasive lobular breast cancer include:

- A lump or 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 of the skin
- A lump or swelling under the arm
- Changes to the nipple
- Discharge from the nipple
- Pain in the breast or armpit that is there all of the time

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

HOW IS IT DIAGNOSED?

Invasive lobular breast cancer can be more difficult to diagnose than other types of breast cancer if there are no obvious symptoms. It will be 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)

Invasive lobular breast cancer can sometimes be more difficult than other types of breast cancer to locate and measure using ultrasound or a mammogram, so you may have a magnetic resonance imaging (MRI) scan of your breast. An MRI scan uses magnetic fields and radio waves to produce a series of images of the inside of the body. It does not expose the body to x-ray radiation.

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.

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

TREATMENT

Surgery

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

The type of surgery recommended may be:

- 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

If breast-conserving surgery is being considered, an MRI scan may be recommended to assess the size of the cancer (if you have not 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 breastconserving 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.

Which type of surgery?

The type of surgery recommended will depend on factors such as:

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

Some people may be offered a choice between breastconserving surgery and a mastectomy. Studies have shown that long-term survival is similar for breast-conserving surgery followed by radiotherapy as for mastectomy alone.

You can talk through your options with your treatment team.

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.

Many women who have a mastectomy without breast reconstruction 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 women choose not to have reconstruction and not to wear a prosthesis after their mastectomy.

Surgery to the lymph nodes under the arm

If you have invasive breast cancer, your treatment team will want to check if any of the lymph nodes (glands) under the arm contain cancer cells. This, along with other information about your breast cancer, helps them decide whether or not you will benefit from any 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

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 sentinel lymph node (the first lymph node that the cancer cells are most likely to spread to), is clear of cancer cells. There may be more than one sentinel lymph node. If clear, this usually means the other nodes are clear too, so no more will need to be removed. Sentinel lymph node biopsy is usually carried out at the same time as your cancer surgery but may be done before.

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

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 may recommend a lymph node clearance.

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

ADJUVANT (ADDITIONAL) TREATMENT

After surgery, you may need other treatments. These are called adjuvant treatments and can include:

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

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

Some of these treatments may be given before surgery. This is known as neo-adjuvant or primary therapy.

Chemotherapy

Chemotherapy destroys cancer cells using anti-cancer drugs. It is 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, its grade (how different the cells are to normal breast cells and how quickly they are growing) and whether the lymph nodes are affected.

It will also depend on the oestrogen receptor and HER2 status. See the sections on 'Hormone (endocrine) therapy' and 'Targeted (biological) therapies' for an explanation of these terms.

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 to reduce the risk of the cancer coming back in the same breast. Some people 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 the lymph nodes under the arm are affected.

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

Hormone (endocrine) therapy

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

Invasive breast cancers are tested to see if they are ER+ using tissue from a biopsy or after surgery. If your cancer is ER+, your specialist will discuss with you which hormone therapy they think is most appropriate.

If your breast cancer is not stimulated by oestrogen it is known as oestrogen receptor negative (ER-), and hormone therapy will not be of benefit.

Tests are also done to see if your breast cancer is progesterone receptor positive (PR+). Progesterone is another hormone. 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 your specialist will discuss with you whether hormone therapy is appropriate.

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

Targeted (biological) 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 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. They are used in combination with chemotherapy.

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

For information about different types of targeted therapies for people with either HER2 positive or HER2 negative breast cancer, see **breastcancernow.org/targeted-therapy**

Bisphosphonates

Bisphosphonates are a group of drugs that can reduce the risk of breast cancer spreading in post-menopausal women (women who have been through the menopause). They can be used regardless of whether 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.

See our bisphosphonate drug booklets, **Zoledronic acid** and **Sodium clodronate**, for more information.

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, 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.

Whether you had breast-conserving surgery or a mastectomy (with or without reconstruction), it is also important to be aware of any changes to the breast, chest or surrounding area.

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 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. With invasive lobular breast cancer, this risk may be slightly higher than with other types of breast cancer, but it is still very low overall. Therefore it is important to be aware of any new changes in the 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 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 do not 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 Now's Helpline on **0808 800 6000** and talk through your diagnosis, treatment and how you are feeling with one of our team.

NOTES

FOUR WAYS TO GET SUPPORT

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



Speak to our nurses or trained experts. Call our free Helpline on **0808 800 6000** (Monday to Friday 9am– 4pm and Saturday 9am–1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.



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.breastcancernow.org**



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



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 **breastcancernow.org/in-your-area**

NOTES	NOTES

SUPPORT FOR TODAY HOPE FOR THE FUTURE

We believe that we can change the future of breast cancer and make sure that, by 2050, everyone diagnosed with the disease lives – and is supported to live well. But we need to act now.

If you found this booklet helpful, use this form to send us a donation.

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Donate using your debit or credit card **breastcancernow.org/donate**

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Keeping in touch with Breast Cancer Now

We'd like to tell you ways you can help further, including through donating, fundraising, campaigning and volunteering, and send you updates on our research, the support we provide, breast health information and our wider work to achieve our aims.

If you already hear from us, we will continue to contact you in the same way. If you don't already hear from us, please tick the box if you are happy to be contacted by:

🗌 Email

□ Mobile messaging

Please return this form to Breast Cancer Now, Freepost RTSC-SJTC-RAKY, Fifth Floor, Ibex House, 42–47 Minories, London EC3N 1DY

How we use your information

From time to time, we may contact you by telephone and post to keep you updated on our work and ways you can help. You can change the way you hear from us at any time by emailing us at supporterengagement@breastcancernow. org or calling us on 0333 20 70 300.

To help us to work more efficiently, we may analyse your information to make sure you receive the most relevant communications, and to target our digital advertising. This may include using publicly available information. You can ask us to stop this at any time, by contacting us using the above contact details. You can read more about how we will use your information on our website at breastcancernow.org/privacy, or contact us if you'd like a paper copy.

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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: Email **health-info@breastcancernow.org**



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We're here for anyone affected by breast cancer. And we always will be.

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

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