

Key facts about Lobular Breast Cancer

- 🔑 Lobular is the second most common form of breast cancer.¹
- 🔑 Due to its unique growth pattern, Lobular rarely forms a lump.
- 🔑 There are different types of Lobular such as classic, mixed, pleomorphic, alveolar and signet-ring which have varied characteristics and may respond differently to treatment.
- 🔑 Most Lobular tumours are slow growing, and they can often be multi-focal or multi-centric meaning that you may have more than one tumour in the same breast.
- 🔑 Lobular can be harder to detect using standard imaging techniques, both in your breasts and the rest of your body, so you may want to ask for additional monitoring methods. Please contact us at LBCUK if you have any questions about this.
- 🔑 The full size of Lobular tumours often cannot be seen using imaging techniques, so do not be surprised if the size of your tumour(s) is(are) larger than it initially appeared on imaging.
- 🔑 Men can get Lobular, but this is very rare.

Where can I find more information?

Lobular Breast Cancer UK (LBCUK) are the UK's only charity with a sole focus on Lobular. We are a group of women who have had our own Lobular diagnoses and now work to: increase the knowledge and understanding of Lobular amongst other patients, clinicians and researchers; collaborate on research; and campaign to ensure that we receive the most appropriate and effective treatments for Lobular. You can find more information and support on our website via the QR code on the back of this leaflet.



How can you support LBCUK:

Campaigning

You can get involved with our campaigns to improve outcomes for anyone with a Lobular diagnosis including **#22ADayUK** and **Distinctly Lobular**, our campaign to change UK treatment guidelines. Find out more and how to get involved on our website.



How can LBCUK support you:

Information and resources

On our website you can find and download accurate and up-to-date information and resources about Lobular to help **increase your knowledge, enhance conversations** with your medical team and **support you through different stages** of diagnosis and treatment.

Support

We provide **online and in-person group support**, and can direct you to appropriate services across the UK and internationally. If you have any questions about Lobular, please contact us by email.

Fundraise or donate to LBCUK

Every pound raised for LBCUK helps us support and improve outcomes for everyone who has a Lobular diagnosis. Your donations help us to continue to provide accurate and free information. Please donate at <https://www.justgiving.com/charity/lobularbreastcancer>

“ I was diagnosed with Lobular Breast Cancer in 2023. LBCUK provided me with the facts and empowered me to take action, and for that I am grateful. ”

Tess, diagnosed with Lobular

15%
of all breast cancer
diagnoses are Lobular
Breast Cancer¹

Lobular Breast
Cancer is a
distinct disease
due to it's unique
growth pattern
which rarely
forms a lump



Scan here!

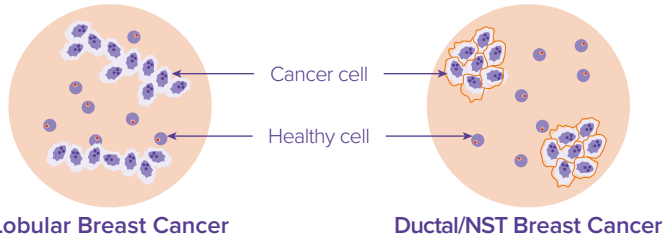
Find out more:

- 🌐 lobularbreastcancer.org.uk
- ✉ info@lobularbreastcancer.org.uk
- 📱 @lobularBCUK
- 📧 @lobularbreastcanceruk

What is Lobular Breast Cancer?

Lobular Breast Cancer (hereafter referred to as Lobular) is a distinct type of breast cancer with different characteristics and growth patterns to the more common Ductal or No Special Type (NST) breast cancer.

Lobular has a unique growth pattern, developing as rows of single cells through healthy breast tissue like a spider's web:



Lobular rarely forms a lump, meaning it can be **harder to detect through self-examination, mammograms and ultrasounds**, particularly for people who have dense breasts. As a result, Lobular can be detected at a later stage than other breast cancers.

If you have been told you have **Lobular hyperplasia or Lobular carcinoma in situ (LCIS)**, these are not cancer. Instead, changes in your breast cells have been detected that indicate a potentially higher risk of developing breast cancer in the future. While this does not mean that you will be diagnosed with breast cancer, your doctor may discuss possible treatment options with you.

Can Lobular Breast Cancer recur?

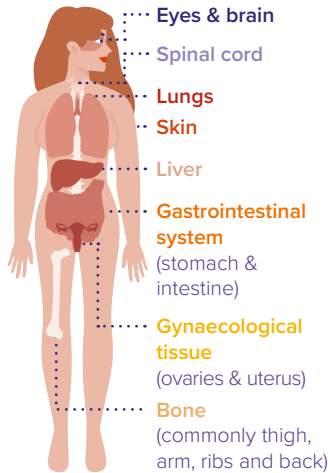
Lobular can recur near the original tumour site in your breast (local recurrence), or in other parts of the body (metastatic recurrence). Whilst most recurrences occur in the first five years, Lobular has the **potential to recur many years after an initial diagnosis.**² Therefore, it is important to keep checking for signs and symptoms beyond your initial treatment.

What is secondary, metastatic or stage 4 Lobular Breast Cancer?

Secondary, metastatic or stage 4 Lobular is when the cancer cells spread beyond the breast. If Lobular spreads, for example, to the ovaries, this is secondary breast cancer and not ovarian cancer.

Although this may sound scary, remember that **most people do not develop metastatic disease** – always reach out to your medical team for psychological support if you are worried.

Areas of the body that Lobular Breast Cancer may spread to include, but are not limited to:^{2,3}



Who is diagnosed with Lobular Breast Cancer in the UK?

Around 22 people are diagnosed with Lobular every day in the UK, making up ~8,400 diagnoses a year. The majority of Lobular diagnoses are in women, with less than 1% in men.³



Even if your risk of Lobular seems low, everyone is different, so always get any symptoms checked by a GP, regardless of your sex, age or race/ethnicity.

What changes should I look for?

Due to its unique growth pattern, rarely forming a lump, it can be hard to detect Lobular by self-examination. These are some of the changes that you might experience. However, everyone is different, so get to know how your breasts **LOOK and FEEL** at various times of the month so you can tell if there are any changes.



Any changes to the nipple shape or direction



Any discharge or oozing from the nipple



Persistent itching on the skin or inside the breast



Tugging or stabbing sensations in the breasts



Lumps on the breast



Any breast skin changes, such as dimpling, puckering or dents



Swelling or unusual fullness of the breasts



Pain in the breasts

What should I do if I notice a change?

Always **look and feel** for visual and physical changes when checking your breasts and armpits. **Do not ignore signs of Lobular. Go and speak to your GP.**

If you have had Lobular before and suspect you may have a recurrence, **go and see your GP** or call your breast care nurse, particularly if you are within 5 years of initial primary diagnosis.

We understand this may be overwhelming and frightening. **If you are worried about your symptoms, talk to someone – this could be a friend or family member, or a trained counsellor or therapist. Keep notes about your symptoms to help you discuss any changes with your GP or medical team.**

If you would like to speak to a specialist breast cancer nurse, call Breast Cancer Now's free helpline on 0808 800 6000 (Monday to Friday 9am–4pm and Saturday 9am–1pm).