

Invasive Lobular Carcinoma: What You Need to Know

Information for Primary Healthcare Professionals

What is Invasive Lobular Carcinoma (ILC)?

ILC, or lobular breast cancer, is the second most common type of breast cancer and accounts for up to 15% of all breast cancers.¹ ILC tumours grow diffusely, with neoplastic cells invading the stroma in a linear growth pattern, like a spider's web.^{1,2} This means ILC tumours rarely form a lump making ILC distinct from the more common invasive ductal, or no special type, carcinoma (IDC/NST).

Unique Challenges for ILC Detection and Diagnosis

The unique linear growth pattern of ILC and the low density of tumour cells means ILC can be difficult to detect through self-examination or standard mammography, the most commonly used tool for routine breast cancer screening. Mammograms have a low sensitivity in detecting ILC (range 57%–81%),^{3,4} with up to 30% of cases not visualised at all with mammography.² When breast tissue is heterogeneous or dense, the sensitivity of mammography for the detection of ILC is typically 30%–48%,² with one study examining mammography in women with dense breast tissue reporting the sensitivity to be as low as 11%.⁵ Because of difficulties detecting ILC, it is not readily picked up during routine breast cancer screenings and tends to be diagnosed at a larger size and later tumour stage.³ Ultrasound scans offer higher sensitivity for detecting ILC compared with mammograms (68%–98%). However, ultrasounds are primarily used as a diagnostic imaging tool once breast cancer is suspected, rather than for routine screening.⁴

How to Spot the Signs of ILC

Given the challenges in detecting ILC in routine breast cancer screening, it is important to be aware of the key signs and symptoms of ILC. If a patient presents without a distinct lump but with any of the following symptoms: hardening or thickening of the breasts, skin changes on the breast, swelling of the breast, tugging/stabbing sensations or consistent breast pain, persistent itching of the breast or changes to nipple shape, direction or any nipple discharge,⁶ **CONSIDER IF THEY COULD BE SIGNS OF ILC.**

How to Support Patients with ILC

ILC can metastasise to different areas of the body compared with IDC/NST,⁷ including the ovaries and uterus, gastrointestinal system, the meninges (lining of the spinal cord and brain) and the eyes, and patients with ILC may already have metastases at the time of diagnosis.³ In addition to metastasis, ILC can also recur locally at a later timepoint than IDC/NST.^{1,2} Whilst most recurrences occur in the first five years, ILC has the potential to recur more than 10 years after an initial diagnosis.⁴ Given the capacity for ILC metastasis and recurrence several years after diagnosis, it is important to provide ongoing support to patients, encouraging those who have previously had ILC to continue monitoring their breasts.

The Key to Change

ILC is not currently recognised as a distinct disease in guidelines from the National Institute for Health and Care Excellence (NICE) or Scottish Intercollegiate Guidelines Network (SIGN) for breast cancer diagnosis and management. You can be the key to change by supporting and getting involved with #DistinctlyLobular, our Lobular Breast Cancer UK Treatment Guidelines campaign, which aims to increase understanding of ILC as a distinct disease and ensure patients are diagnosed early and receive the most effective treatments.



Want to know more?

Please visit our Lobular Breast Cancer UK website lobularbreastcancer.org.uk or contact us on info@lobularbreastcancer.org.uk