Hereditary risk and ILC

Hereditary breast cancer is rare in patients with ILC (<5%). The likelihood of a hereditary cause is higher in patients with a younger age, with a tumour in both breasts or a family history of certain cancers.

Key concepts and additional information

- **Hormone sensitivity:** tumour cells can express hormone receptors, which are proteins that bind hormones and provide signals to the cell to grow. Breast cancer cells can express hormone receptors that bind oestrogen, progesterone or androgenic hormones (like testosterone).
- **Endocrine treatment:** also called anti-hormone treatment, used for hormone sensitive tumours, directed against the production of hormones or against hormone receptor function.
- **Aromatase inhibitors:** type of anti-hormone treatment that will reduce the amount of oestrogen made in the body of postmenopausal women.
- **Breast surgery:** this can consist of either removal of the entire breast (= mastectomy) or removal of the tumour only (= breast conserving surgery).
- **Chemotherapy:** cancer treatment that uses one or more anti-cancer drugs that stop or slow down the growth of cancer cells.
- **Radiotherapy:** cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumours.
- **Targeted therapy:** treatment that blocks the growth of cancer cells by attacking specific (targeted) proteins within the cell, for example hormone receptors or the HER2 protein.
- **Clinical trial:** a study in which patients are assigned to one or more treatments (which may include placebo or other control) to evaluate the effects on the disease.
- **Relapse:** re-occurrence of disease at the side of primary disease (loco-regional relapse) or a distant organ (distant relapse, also called metastatic relapse).
- **E-cadherin:** the major adhesion molecule in breast epithelial cells. Inactivation of E-cadherin results in loss of cell-to-cell adhesion. E-cadherin loss causes ILC and is responsible for the characteristic growth pattern of ILC.

European Lobular Breast Cancer Consortium

Do you have any questions after reading this leaflet?
Feel free to contact your medical team!
For more information, please visit
www.elbcc.org or **www.lobsterpot.eu**
Additional recommended website:
https://lobularbreastcancer.org – LBCA
(Lobular Breast Cancer Alliance)

Or scan the QR-code for more information

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WHAT IS LOBULAR BREAST CANCER

What is LOBULAR breast cancer (ILC)?

When you (or a family member) get diagnosed with breast cancer, you might be overwhelmed by all the medical information. You have been diagnosed with invasive lobular breast cancer (ILC), a special type of breast cancer. ILC can behave and present itself in different ways to what you may have heard and may think about breast cancer. With this leaflet, we provide you with an overview of the basic information regarding ILC. Hopefully, it can answer some of your questions. We encourage you to further discuss your disease and treatment options with your medical team.

What is lobular breast cancer (ILC)?

15% of women with breast cancer have ILC. A typical feature of ILC is that it grows in rows of single cells because the cancer cells do not stick to each other as in other breast cancers. Fortunately, most patients with ILC respond well to anti-hormone (endocrine) treatment. The special features of ILC and how it distinguishes itself from non-ILC breast cancer are summarized in the following table.

Main differences with non-ILC breast cancer

Detection with imaging	More difficult to identify on mammography and ultrasound, especially in dense breasts Detailed magnetic resonance (MRI) imaging is recommended
Clinical features	More often, multiple lobular tumours can form in the same breast and/or in the other breast at the same time Most tumours (>90%) can be treated with anti-hormone treatment Only a few tumours (5%) can be treated with anti-HER2 treatment
Metastases (= presence of ILC in other organs)	The majority of patients with ILC can be successfully treated but metastases can occur, sometimes early (within 10 years after diagnosis), sometimes late (>10 years) or very late (>20 years) If metastases develop, they can be present in organs such as the digestive organs (stomach/intestines) and/or reproductive organs (uterus/ovaries), in addition to lungs, liver, bones and brain

Treatment in the early setting

In the early setting, ILC is only present in the breast and possibly the nearby lymph nodes. There are no signs of metastases in other organs. Breast cancer can be treated locally using surgery and radiotherapy, and systemically with for example chemotherapy and anti-hormone (endocrine) therapy. Local treatment aims to remove the cancer from a specific area, in this case the breast and the nearby lymph nodes. Systemic treatment will distribute itself throughout the entire body to attack cancer cells that may have spread in the body. This treatment aims to reduce the risk of the cancer recurring in other organs.

Local treatment:

- **Surgery:** when there are multiple tumours in your breast, there is a greater chance that your entire breast needs to be removed (= mastectomy), which is more commonly performed for patients with ILC.
- **Radiotherapy:** it depends on the type of surgery you had and whether tumour cells are present in local lymph nodes if you need local radiation treatment.

Systemic treatment:

- **Endocrine treatment:** the chance that you need anti-hormone treatment is very high, since most ILC tumours are sensitive to hormones. Aromatase inhibitors are the preferred endocrine treatment option for ILC.
- **Chemotherapy:** although ILC has a tendency to not respond well to chemotherapy, this treatment option needs to be decided together with your doctor.
- **Anti-HER2 treatment:** this targeted therapy will be proposed to you if your tumour overexpresses a marker called HER2. In ILC, this is a minority group.
- **Bisphosphonates:** this class of drugs (commonly used to treat osteoporosis) can possibly be added to your treatment if you are menopausal.

Treatment plans can differ. Sometimes systemic treatment is given before the surgery to try to shrink the tumour, this is called **neo-adjuvant treatment**. When the systemic treatment is given after surgery to prevent metastasis, it is called **adjuvant treatment**. Ongoing clinical trials can also provide additional treatment opportunities before and after surgery.

Treatment in the metastatic setting

ILC is called metastatic when it has spread through the body and forms secondary tumours. Metastatic ILC can be present at the time of diagnosis or develop at a later phase. The majority of the treatments used in the metastatic setting will be systemic and aim to control the growth of the cancer as long as possible. Local treatments like surgery and radiotherapy can be used to obtain local control of some metastases. This can help in giving pain relief for example.

- There is no fixed sequence of treatment regimens: every case needs to be discussed individually.
- First treatment options often exist of anti-hormone treatments and/or chemotherapy. In some cases, the addition of a targeted treatment is optional.
- Ongoing clinical trials can provide additional treatment opportunities.