This booklet is about lobular neoplasia, which includes atypical lobular hyperplasia (ALH) and lobular carcinoma in situ (LCIS). It explains how it is diagnosed and treated.
This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer and concerned about breast health.

We offer reliable information and personal support, over the phone and online, from nurses and people who’ve been there.

We highlight the importance of early detection and we’re here to answer your questions about breast health and breast cancer.

For care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk
What is lobular neoplasia?

Lobular neoplasia is a condition that affects the lobules in the breast. Breasts are made up of lobules (milk-producing glands) and ducts (tubes that carry milk to the nipple) which are surrounded by glandular, fibrous and fatty tissue.

When lobular neoplasia occurs, there is an increase in the number of cells contained in the lobules, together with a change in their appearance and behaviour.

The breast

Types of lobular neoplasia

The most common forms of lobular neoplasia are atypical lobular hyperplasia (ALH) and lobular carcinoma in situ (LCIS). ‘In situ’ means the changes only occur in the breast lobules and do not affect the surrounding tissue. You may hear ALH and LCIS referred to as ‘classical lobular neoplasia’.

Very rarely, LCIS may be made up of larger, more abnormal cells. This is known as pleomorphic LCIS (PLCIS).
Who it affects

Lobular neoplasia is mostly found in women aged 40–50 who haven’t yet been through the menopause. However, some cases are found in post-menopausal women during routine breast screening, often on their first mammogram (breast x-ray).

Lobular neoplasia can be found in men, but this is extremely rare.

How lobular neoplasia is diagnosed

Most women with lobular neoplasia have no symptoms. It’s usually discovered by chance, either when a breast biopsy is taken for another reason, such as a breast lump, or when calcifications (small spots of calcium) are detected on a mammogram. It’s believed that many cases of lobular neoplasia go undiagnosed and never cause any symptoms.

When looked at under a microscope, ALH and LCIS can look very similar. It’s sometimes difficult to separate the two conditions and in this case it will be described as lobular neoplasia.

Future breast cancer risk

The vast majority of women diagnosed with ALH or LCIS will never get breast cancer. However, people diagnosed with either condition have a slightly higher risk than the general population of developing breast cancer.

PLCIS behaves differently to ALH and LCIS, and may be more likely to develop into cancer in the future.

Your individual risk depends on several factors, which your specialist can talk to you about.
Treatment and follow-up

There is no standard recommended treatment or follow-up for lobular neoplasia. Your specialist will discuss treatment options with you based on your particular situation.

If your lobular neoplasia is diagnosed by a core biopsy, your doctor may recommend removing more tissue from the area where the lobular neoplasia was found. This is to find out if there are any cancer cells in this area. This may be done using a procedure called a vacuum assisted biopsy, or a small operation known as an excision biopsy.

However, if the biopsy shows PLCIS, your doctor may suggest an operation to remove the area because of the higher breast cancer risk with this type of lobular neoplasia. The operation will show if there are any cancer cells in the tissue, and whether all the PLCIS has been removed.

Although most women who are diagnosed with lobular neoplasia do not develop breast cancer, your specialist will usually recommend having yearly follow-up mammograms for up to five years. This aims to find any further changes as early as possible. Your specialist will discuss which follow-up is best for you.

Sometimes further scans may be recommended, such as an MRI (magnetic resonance imaging) scan, if you have other risk factors for breast cancer such as a significant family history of breast cancer.

Rarely, some women choose to have a risk-reducing bilateral mastectomy (surgery to remove both breasts), with or without breast reconstruction. This may be because they have a strong family history of breast cancer or they feel they cannot cope with the uncertainty and anxiety of having lobular neoplasia.

You can find out more about family history in our Breast cancer in families booklet, and about breast reconstruction following a mastectomy in our Breast reconstruction booklet.

Research has shown that treating women who have lobular neoplasia with tamoxifen (a hormone therapy treatment for breast cancer) can reduce the risk of breast cancer developing. However, any possible benefit of taking tamoxifen needs to be considered against the risks and side effects of this treatment. Your specialist will discuss this with you if this might be an option.
**What this means for you**

Finding out that you have lobular neoplasia can leave you feeling a number of different emotions. Fear, shock and anger are all common feelings at this time. Although lobular neoplasia is not breast cancer, it can cause uncertainty about possible future risk for cancer. You may have times when you feel anxious or concerned about your future risk.

There are people who can support you, so don’t be afraid to ask for help. Let other people know how you are feeling, particularly your family and friends. It can also help to discuss your feelings or worries with your specialist team. If you want to talk through your feelings in more depth over a period of time, a professional counsellor might be more appropriate. Your specialist, breast care nurse or GP (local doctor) will usually be able to arrange this.

The Breast Cancer Care Helpline on **0808 800 6000** (Text Relay **18001**) can also give you support and information.
We’re here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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Please return this form to Breast Cancer Care, Freepost RRKZ-ARZY-YCKG, 5–13 Great Suffolk Street, London SE1 0NS
About this booklet

Lobular neoplasia was written by Breast Cancer Care’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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If you have a breast cancer or breast health query contact our Helpline on 0808 800 6000 or visit breastcancercare.org.uk