THE CANCER THAT'S HARD TO DETECT

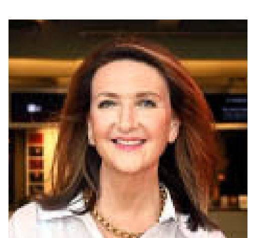
More difficult to notice and poorly understood, lobular breast cancer is finally coming under the spotlight

Lobular breast cancer, also known as invasive lobular carcinoma (ILC), is more common than ovarian and skin cancer yet there is little awareness of it. According to Cancer Research UK, one in seven women will be diagnosed with breast cancer in their lifetime and around 15% of those will have ILC. BBC presenter Victoria Derbyshire, 56, was diagnosed with the disease in 2015.

ILC is different to the most common form of ductal breast cancer. Instead of starting in the breast ducts, it starts in the lobules, the glands that produce milk, and grows in a spider's web pattern. Cancer cells infect the tissue around the glands and rarely show in lumps, so it is harder to spot and likely to be diagnosed later.

At least a fifth of ILC cases return years later. When this happens, the cancer becomes even harder to treat. And yet it's an under-diagnosed subtype of breast cancer that is underfunded and poorly understood.

Kate Ford, a campaigner from the Lobular Moon Shot Project (LMSP), says, "The basic biology of this disease has never been studied and it has no specific treatment. ILC needs a moon shot approach - a fast injection of cash - to research funding."



Victoria Derbyshire

On 24 June, 22 women led by LMSP Founder Dr Susan Michaelis, who sadly passed away from ILC on 9 July, held a vigil outside 10 Downing Street and delivered a petition backed by more than 350 MPs to the Prime Minister, calling for urgent funding for ILC research.

The Macmillan Support Line offers free, confidential support to people living with cancer and their loved ones. Call for free within the UK on 0808 808 0000

1 SYMPTOMS TO WATCH OUT FOR

Lobular breast cancer rarely forms lumps. Instead, the things to look out for include an area of thickening or swelling around the breast, a change in the nipple, for example it becoming inverted, or a change in the skin, such as dimpling, puckering or even a small new mark.

2 DON'T IGNORE OTHER CHANGES

Cancer Research UK suggests people should also look out for pain and itching, a new lump in your breast or armpit, a change in the size, shape or feel of your breast, skin changes in the breast such as a rash or redness of the skin, fluid leaking from the nipple in a woman who isn't pregnant or breastfeeding and/or changes in the position of the nipple. If you see any of these symptoms you're advised to visit your doctor.

3 GET A DIAGNOSIS

Your GP will refer you to a clinic if they believe you might have ILC. They will examine your breasts and check for swollen lymph nodes. They may use a mammogram, an ultrasound if you're under 35, a biopsy or an MRI scan. MRI and biopsy are the most effective detection tools for ILC. Mammograms and ultrasound often fail to show the presence of the disease.

4 HOW ILC IS TREATED

ILC is currently treated with chemotherapy, surgery and drugs to reduce the level of oestrogen, which cancer cells need to grow. Chemo works best on fast-dividing cells, but lobular breast cancer is not fast dividing, so the efficacy of chemo on ILC is not entirely understood.

Depending on the size and abnormality, whether cells have receptors for drugs, your general health and age, a doctor will consider the best treatment, but generally it is the same as for the more common types of breast cancer.

5 HOPE FOR THE FUTURE

The Lobular Moon Shot Project is campaigning to raise £20m in government funding to carry out vital research on ILC in partnership with the Manchester Breast Centre and led by breast biology expert Professor Rob Clarke. "With this funding, we could potentially develop a drug and begin testing it on patients within the next five years," he says.

'THE FEAR OF RECURRENCE IS ALWAYS WITH ME'

Lobular Moon Shot Project campaigner, teacher and mum-of-three Katie Swinburne, 49, was diagnosed with ILC in 2023

"Prior to my diagnosis, I was extremely fit and healthy, and took care with the food I ate. I remember the morning I found a lump very clearly. It appeared overnight after two years of other symptoms including pain and itching. It was extremely large, but in my ignorance I thought it was a cyst.

"I went to see my GP and was sent to have a mammogram, then an ultrasound. The sonographer felt the lump but was confident there was nothing to worry about. He performed a biopsy to try and establish what the lump was.

"At my next appointment, a consultant came in, followed by a nurse. I was soon to learn the nurse was a Macmillan nurse. I was smiling and chatting away to the consultant, expecting to be sent on my way, when he said, 'We have the results – you have an invasive lobular carcinoma.'

"Hearing the words 'you have cancer' is like nothing else. My life, my body and my future were no longer assured. At the time of my diagnosis, my children were 10, 12 and 14. The thought of leaving them left me breathless.

"A whirlwind of appointments followed, including CT, MRI and DEXA scans. I had a double mastectomy and dose-dense chemotherapy, then radiotherapy. The nurses are angels. They hold your hand through it all. You find reserves you never knew you had.

"The fear of recurrence is always with me. I'm two years on from diagnosis and still too young for screening. Had that lump not appeared, my story might be very different. I think we need to start education and screening at a much younger age."

WORDS: ALI GRAVES PHOTOS: GETTY IMAGES