Ductal carcinoma in situ (DCIS)



This booklet is for people who would like more information about ductal carcinoma in situ (DCIS). It describes what DCIS is, the symptoms, how a diagnosis is made and possible treatments.

This information is by Breast Cancer Care.

We are the only specialist UK-wide charity that supports people affected by breast cancer. We've been supporting them, their family and friends and campaigning on their behalf since 1973.

Today, we continue to offer reliable information and personal support, over the phone and online, from nurses and people who've been there. We also offer local support across the UK.

From the moment you notice something isn't right, through to treatment and beyond, we're here to help you feel more in control.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk



We hope this information helps you understand more about DCIS, discuss any questions you have with your specialist team and be involved as much as you want in any decisions about your treatment.

You may also find it useful to read our **Treating primary breast cancer** booklet.

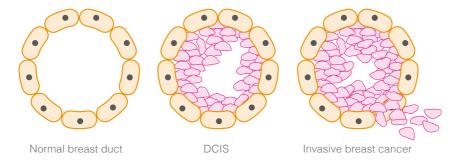
What is DCIS?

DCIS is an early form of breast cancer and accounts for about 12% of all breast cancers.

Breast cancer starts when cells in the breast begin to divide and grow in an abnormal way.

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 cancer cells have developed within the ducts of the breast but remain within the ducts ('in situ'), it is called DCIS. The cancer cells have not yet developed the ability to spread outside these ducts into the surrounding breast tissue or to other parts of the body. As a result of being confined to the ducts, DCIS has a very good prognosis (outlook).



You may hear DCIS described in different ways such as a pre-invasive, intraductal, non-invasive cancer, or Stage 0 breast cancer.

What are the symptoms?

DCIS usually has no symptoms. Most cases of DCIS are found during routine breast screening or if a mammogram (breast x-ray) is done for some other reason.

Occasionally DCIS is found when people have a breast change such as a lump or discharge from the nipple. However, if someone with DCIS has a breast change it's more likely they will also have an invasive breast cancer (see page 7).

Some people with DCIS also have a type of rash involving the nipple known as Paget's disease of the breast, although this is rare. For more information see our website.

Diagnosis

DCIS is diagnosed using a range of tests, which may include one or more of the following:

- breast examination
- mammogram (breast x-ray)
- ultrasound scan (uses high frequency sound waves to produce an image)
- biopsy (removal of tissue to be looked at under a microscope)

Diagnosing calcifications

If you have no symptoms and are recalled following a mammogram it may be because some tiny white dots were seen on the mammogram. These white dots are spots of calcium salts called calcifications. Calcifications can be due to DCIS. However, not all calcifications are found to be DCIS. Many women develop benign (not cancer) calcifications in their breasts as they get older.

If you have calcifications, further mammograms will be done to see the calcifications in more detail. Sometimes an ultrasound will also be done.

If the calcifications are not clearly benign, you'll have an image-guided biopsy to help make a diagnosis. This is where samples of breast tissue are taken using a mammogram to help locate the exact position of the calcifications. Sometimes an ultrasound is used but this is less common. It's done as an outpatient procedure so you'll be able to leave soon after. The biopsy samples will be x-rayed to check if they contain calcifications before being sent to the laboratory to be examined under a microscope.

If you'd like more information about these tests see our booklet **Your** breast clinic appointment.

Inserting a metal marker

If you have a biopsy, sometimes a small metal clip (or marker) is placed in the breast where the biopsy samples were taken. This is so the area can be found again if another biopsy or surgery is needed. It can safely be left in the breast and does does not need to be removed, even if no further procedures are needed.

Getting your results

The staff at the clinic will tell you how and when you will get your biopsy results. You will usually be given an appointment to return to the clinic for your results.

How results are described

DCIS is graded based on what the cells look like under the microscope. They will be given a grade according to how different they are to normal breast cells and how quickly they are growing. DCIS is graded as low, intermediate, or high grade.

- low grade the cancer cells look most like normal cells and are usually slow-growing
- intermediate grade the cancer cells look less like normal cells and are growing faster
- high grade the cancer cells look most changed and are usually fast-growing

For more information see our booklet **Understanding your** pathology results.

Can DCIS develop into invasive breast cancer?

If DCIS is left untreated, the cancer cells may develop the ability to spread outside the ducts, into the surrounding breast tissue. This is known as invasive breast cancer. Invasive cancer has the potential to also spread to other parts of the body.

For more information see our **Invasive ductal breast cancer** booklet.

In some cases, DCIS will never develop further or grows so slowly that it would never cause harm during that person's lifetime. Although the size and grade of the DCIS can help predict if it will become invasive, there is currently no way of knowing if this will happen. High-grade DCIS is more likely to become an invasive breast cancer than low-grade DCIS and do so more quickly.

How is DCIS treated?

The aim of treatment is to remove all the DCIS from within the breast to reduce the chance of it becoming an invasive cancer.

Because there's no way of knowing when or if DCIS will become invasive, treatment is usually recommended. It is possible that this may lead to unnecessary or overtreatment for some people.

Research is ongoing to identify which cases of DCIS will go on to become invasive and which might be safe to leave untreated. If you are diagnosed with low-grade DCIS, you may be invited to join a clinical trial.

If you have any questions or concerns about your diagnosis and treatment, talk to your specialist team.

Surgery

Surgery is nearly always the first treatment for DCIS. This may be breast-conserving surgery or a mastectomy.

Breast-conserving surgery, also known as a wide local excision or lumpectomy, is the removal of the DCIS with a margin (border) of normal breast tissue around it. A mastectomy is the removal of all of the breast

tissue including the nipple area. A nipple-sparing mastectomy may be possible in some cases. You may wish to ask your specialist team about this.

You may be offered a choice between these types of surgery, depending on the size and location of the area affected. Your breast surgeon will discuss this with you.

A mastectomy is more likely to be recommended if:

- the DCIS affects a large area of the breast
- the DCIS is in more than one part of the breast (although if the areas are small, it may be possible to have two wide local excisions instead of a mastectomy)
- it hasn't been possible to get a clear margin of normal tissue around the DCIS using wide local excision

If you have breast-conserving surgery, the breast tissue removed during surgery is examined by a pathologist (a doctor who analyses tissue and cells). If any cancer cells are seen at or close to the margin, you may need more surgery to get a clear margin.

If a mastectomy is not recommended but you would prefer to have one, you can discuss this with your surgeon.

Localisation

As most cases of DCIS can't be felt, a procedure called localisation is often used on the day before or the day of breast-conserving surgery. This takes about 30 minutes and helps mark the exact area to be removed during surgery. Using a mammogram (breast x-ray) or an ultrasound as a guide, a very fine wire is inserted into the area of concern. When a mammogram is used, your breast is compressed throughout the procedure. You'll be given a local anaesthetic to numb the area but you may still feel some discomfort. Once the wire is inserted, a mammogram is taken to check that it is in the correct position. Once the wire is in the correct place, it's secured with a padded dressing and left there until surgery when it's removed.

Some hospitals are using a new localisation procedure where instead of a fine wire, a tiny, very low dose radioactive seed (about the size of a grain of rice) is inserted into the breast tissue. This can be done up to two weeks before your operation. During surgery a special probe is used to locate the seed and guide the surgeon to the tissue that needs to be removed along with the seed.

Breast reconstruction

If you're having a mastectomy you'll usually be able to have breast reconstruction. This can be done at the same time as your mastectomy (immediate reconstruction) or months or years later (delayed reconstruction). If you'd like more information see our Breast reconstruction booklet.

Some women choose not to or cannot have a breast reconstruction. They may use a breast prosthesis (an artificial breast form) that replaces the shape of a breast, or may prefer not to use anything. See our booklet Breast prostheses, bras and clothes after surgery for more information about this.

Lymph node removal

Most people with DCIS won't have surgery to remove the lymph nodes. People with invasive breast cancers will usually have lymph node removal, to check if any of the lymph nodes under the arm (axilla) contain cancer cells. This helps decide whether or not any additional treatment will be of benefit.

Lymph node removal is not usually recommended for people with DCIS because the cancer cells haven't developed the ability to spread outside the ducts into the surrounding breast tissue and therefore cannot have spread to the lymph nodes.

However, if you're having a mastectomy your specialist may discuss having a sentinel lymph node biopsy at the same time as it can be more difficult to assess later if invasive breast cancer is found

Sentinel lymph node biopsy identifies whether the first lymph node (or nodes) is clear of cancer cells. If it is, this usually means the other nodes are clear too, so no more will need to be removed.

If the results of the sentinel lymph node biopsy show that the first node or nodes are affected, more surgery or radiotherapy to the remaining lymph nodes may be recommended.

Sometimes an area of invasive breast cancer is found as well as DCIS. If so, it will affect the treatment(s) you're offered and you may need surgery to the lymph nodes under the arm to check if they contain cancer cells. For more information see our booklet **Treating primary breast cancer**.

Adjuvant (additional) treatments

After surgery, you may need other treatments. These are called adjuvant treatments and can include radiotherapy and, in some cases, hormone therapy.

The aim of these treatments is to reduce the risk of DCIS coming back or an invasive cancer developing.

Chemotherapy and targeted (biological) therapy are not used as treatment for DCIS.

Radiotherapy

Radiotherapy uses high energy x-rays to destroy cancer cells. If you've had breast-conserving surgery you may be offered radiotherapy. It is usually unnecessary to have radiotherapy after a mastectomy for DCIS.

It's given to you as an outpatient, about four to six weeks after your surgery. It's usually given daily (Monday to Friday) for three weeks.

Your specialist will explain the likely benefits of radiotherapy for you and also tell you about any possible side effects. For more information see our Radiotherapy for primary breast cancer booklet.

Hormone (endocrine) therapy

A number of hormone therapies work in different ways to block the effect of oestrogen on cancer cells. Hormone therapy will only be prescribed if your breast cancer has receptors within the cell that bind to the hormone oestrogen, known as oestrogen receptor positive or ER+ breast cancer. When oestrogen binds to these receptors, it can stimulate the cancer to grow. If oestrogen receptors are not found it's known as oestrogen receptor negative or ER- and hormone therapy will not be of benefit.

All invasive breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery. Tests may also be done for progesterone (another hormone) receptors. DCIS may be tested for these hormone receptors but it's not always done.

The benefits of hormone therapy for people with ER+ DCIS vary according to what other treatment is given and it isn't recommended for everyone. If your DCIS is tested and found to be ER+, your specialist will discuss the use of hormone therapy with you. A drug called tamoxifen, or drugs called aromatase inhibitors (for postmenopausal women), may be recommended for some women.

Some studies have found taking hormone therapy after surgery reduces the risk of DCIS coming back (recurrence) and the risk of invasive breast cancer developing, but the women taking it did not live longer than those who didn't take it.

If you would like more information, please see our **Tamoxifen** and Treating primary breast cancer booklets, or our individual booklets on different types of aromatase inhibitors.

Coping with DCIS

Being told you have DCIS can be a difficult and worrying time. Everyone reacts differently to their diagnosis and has their own way of coping.

Although DCIS is an early form of breast cancer with a very good prognosis, people understandably may feel very anxious and frightened by the diagnosis. People can often struggle to come to terms with being offered treatments such as a mastectomy, at the same time as being told their DCIS may never do them any harm.

Some people are reluctant to say they're anxious about a diagnosis of DCIS because they worry others will see it as less important than other types of breast cancer, or that they shouldn't complain because they're not having chemotherapy. Because of this they might feel less able to ask for support. But there are people who can support you so don't be afraid to ask for help if you need it. By letting other people know how you feel, particularly your family and friends, they can be more supportive.

Some people find it helpful to discuss their feelings and concerns with their breast care nurse or specialist. If you'd like to talk through your feelings and concerns in more depth over a period of time, a counsellor or psychologist may be more appropriate. Your breast care nurse, specialist or GP can arrange this.

If you want to talk you can also call our Helpline on 0808 800 6000. You may also find our booklet Breast cancer and you: diagnosis, treatment and the future helpful.



Four ways to get support

We hope this information was helpful, but if you have questions, want to talk to someone or read more about breast cancer, here's how you can.



Speak to our nurses or trained experts. Call our free Helpline on 0808 800 6000 (Monday to Friday 9am-4pm and Saturday 9am-1pm). The Helpline can also put you in touch with someone who knows what it's like to have breast cancer.



Chat to other women who understand what you're going through in our friendly community, for support day and night. Look around, share, ask a question or support others at forum.breastcancercare.org.uk



Find trusted information you might need to understand your situation and take control of your diagnosis or order information booklets at breastcancercare.org.uk



See what support we have in your local area. We'll give you the chance to find out more about treatments and side effects as well as meet other people like you.

Visit breastcancercare.org.uk/in-your-area

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.

Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

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policy at breastcancercare.org.uk or contact supporter services on 0345 092 0800.

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About this booklet

Ductal carcinoma in situ (DCIS) 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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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on 0808 800 6000 or visit breastcancercare.org.uk

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