# Understanding ductal carcinoma in situ (DCIS)



### **About this booklet**

This booklet is about ductal carcinoma in situ, usually called DCIS for short. DCIS is the earliest possible form of breast cancer.

DCIS is non-invasive. This means the breast cancer cells are contained in the ducts and lobules. They have not spread into surrounding breast tissue.

DCIS can occur in anyone, but it is very rare in men. We have information online for men who have been diagnosed with breast cancer at macmillan.org.uk/breast-cancer-in-men

If you are transgender (trans) or non-binary, you may find the information in this booklet useful. We also have more information for trans and non-binary people on our website. Visit macmillan.org.uk/transgender

We hope this booklet helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

We also have a booklet called Understanding breast cancer, which is about early and more advanced breast cancer in women. People who are transgender (trans) or non-binary may find this booklet useful too.

#### How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready. At the end of the booklet, there are details of other organisations that can help.

#### Quotes

In this booklet, we have included quotes from people who have had DCIS, which you may find helpful. To share your experience, visit macmillan.org.uk/shareyourstory

#### For more information

I If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00.

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# The breasts and DCIS

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### The breasts

Breasts are made up of:

- fatty tissue
- supportive (connective) tissue
- glandular tissue containing lobules.

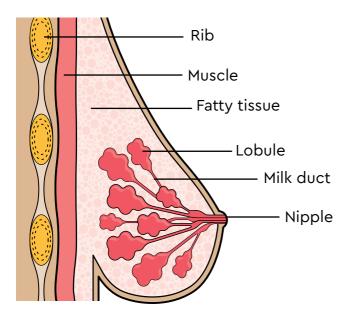
The lobules are also called milk glands. They are where breast milk is made. They connect to the nipple by a network of fine tubes called ducts.

The tissue of the breast extends into the lower armpit (axilla). This area contains lymph nodes (glands). Lymph nodes are part of the lymphatic system, which protects us from infection and disease. We have more information about the lymphatic system on our website. Visit macmillan.org.uk/lymphatic-system

It is common for your breasts to be a different size or shape from each other. If you have periods, you may notice your breasts change at different times of the month. Breasts also change during pregnancy and the menopause. These changes are linked to the different levels of the hormones oestrogen and progesterone. These hormones are made in the body.

Before your period, your breasts may feel tender and lumpy. During pregnancy, breasts go through a lot of changes. After the menopause, when the body makes less oestrogen, breasts may change in size and feel softer or less full. It is important to be aware of how your breasts feel and look at different times. You should know what is normal for you. Always contact your doctor if you notice anything unusual for you, or if there is something you are not sure about.

#### Side view of the breast



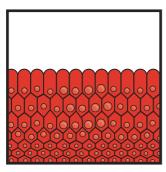
# What is ductal carcinoma in situ (DCIS)?

To understand DCIS, it helps to know how cancer usually develops.

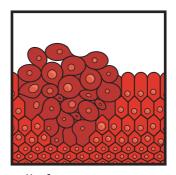
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

#### Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue and can sometimes spread to other parts of the body.

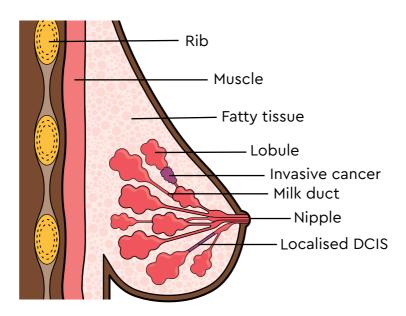
Breast cancer usually starts in the cells that line the:

- lobules, where milk is made
- ducts that carry milk from the lobules out through the nipple.

In DCIS, the lining of the lobules and ducts is replaced by abnormal cells. The cells are completely contained in the ducts and lobules. They have not broken through the walls of the lobules or ducts, and they have not spread into surrounding breast tissue. This is because the cells are not yet able to invade other tissue.

DCIS is the earliest changes to cells which might then become breast cancer. It is not a life-threatening condition. But treatment is usually recommended to stop it developing into breast cancer.

#### Side view of the breast showing DCIS



#### DCIS and invasive breast cancer

If DCIS is not treated, over time there may be more changes to the cells. This means it may spread into (invade) the breast tissue surrounding the ducts. It then becomes an invasive breast cancer. Not every untreated DCIS will develop into invasive breast cancer. But doctors usually advise treating DCIS. This is because it is not possible to tell for certain which cases of DCIS will become invasive cancer.

Having DCIS means you have a slightly higher risk of getting cancer elsewhere in the same breast or in your other breast.

We have more information about invasive breast cancer on our website. Visit macmillan.org.uk/ breastcancer





# Planning your treatment

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# Finding out you have DCIS

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Because DCIS does not usually cause symptoms, your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with DCIS. We have more information about possible causes, risk factors and symptoms of DCIS at macmillan.org.uk/dcis

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have.

You might choose to spend some time reading about DCIS, or you may prefer to wait until cancer doctor can tell you more. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. They will be able to talk to you about what has happened. They can help with any worries you may have.

# Planning treatment for DCIS

Your cancer doctor needs certain information about the DCIS to help plan the best treatment for you. This includes:

- the size of the DCIS
- whether it is only in 1 part of the breast
- the grade of the DCIS
- whether the DCIS has certain hormone receptors.

DCIS describes the earliest changes to cells that might become breast cancer. With invasive breast cancer, the stage usually describes the size of the cancer and where it started. But with DCIS, there is no invasive breast cancer. So it is described as stage 0. This is the earliest stage. DCIS can be any size, but will always be stage 0.

#### **Grading**

The grade of a cancer describes how the cells look and how guickly they grow compared with normal cells. In DCIS, the grade of the cells is important. It indicates how likely DCIS is to come back in the breast. It also indicates how likely it is to develop into an invasive cancer.

There are 3 grades.

#### **Grade 1 (low-grade DCIS)**

The cells look similar to normal breast cells and usually grow slowly. They are less likely to spread into surrounding tissue.

#### Grade 2 (moderate- or intermediate-grade DCIS)

The cells look more abnormal and grow slightly faster than low-grade DCIS.

#### **Grade 3 (high-grade DCIS)**

The cells look guite different from normal breast cells and grow more quickly.

High-grade DCIS is more likely to come back or develop into invasive cancer. Low-grade DCIS can still develop into invasive cancer, but the risk is low. Most people treated for high-grade DCIS have no further problems.

Knowing the grade of the DCIS helps you and your doctors decide on the best treatment for you.

#### DCIS with microinvasion

The pathologist will examine the tissue to see whether the cells have started to spread through the walls of the <u>lobules or ducts</u>. These very small areas of spread are called areas of microinvasion.

#### **Hormone receptors**

DCIS cells may have receptors on them. These allow hormones such as oestrogen to attach to the cancer cell. These hormones can help cancer cells grow. A pathologist checks for receptors by testing the tissue that was removed during the biopsy or surgery.

<u>Hormonal therapy drugs</u> can reduce levels of oestrogen in the body. If the DCIS is oestrogen receptor positive (ER positive), your doctor may suggest hormonal therapy to shrink the DCIS before or after surgery.

After screening, I was diagnosed with high-grade DCIS. I was told they caught it early, so I wouldn't need any scans but could only have the mastectomy. Due to the size of the DCIS, a lumpectomy wasn't an option.

Sienna, diagnosed with high-grade DCIS

#### Treatment overview

The main treatment is surgery to remove the DCIS. Not all DCIS will develop into invasive breast cancer. The aim of treatment is to remove it and reduce the risk of it developing into invasive cancer.

You may also be offered other treatments such as radiotherapy and hormonal therapy.

#### Surgery

Your surgeon may talk to you about having 1 of these operations:

- breast-conserving surgery the surgeon removes the DCIS and some surrounding normal breast tissue
- a mastectomy this surgeon removes the whole breast.

The most common type of surgery for DCIS is breast-conserving surgery. This surgery aims to keep as much of the breast and its shape as possible.

Your surgeon may advise you to have a mastectomy. If you have a mastectomy, you will usually have a sentinel lymph node biopsy. This is a way of checking a few lymph nodes in the armpit for cancer cells.

If you have a mastectomy, you may be able to have a new breast shape made during the operation. This is called breast reconstruction. You can choose to have it done later. We have more information about this in our booklet Understanding breast reconstruction.

#### Radiotherapy

After breast-conserving surgery, your cancer doctor will usually advise you to have <u>radiotherapy to the rest of the breast</u>. This is to reduce the risk of DCIS coming back or invasive breast cancer developing.

#### **Hormonal therapy**

If you have DCIS that is ER positive, your doctor may talk to you about having <u>hormonal therapy</u>.

It is important to talk to your cancer doctor about the possible benefits of hormonal therapy. These should be considered alongside the side effects. Your cancer doctor or nurse can help you decide whether hormonal therapy is a suitable treatment for you.

Doctors are researching whether it is safe for <u>low-grade DCIS</u> to have less treatment. Your cancer doctor or nurse can give you more information about clinical trials that may be suitable for you.

We have more information about clinical trials on our website. Visit <a href="mailto:macmillan.org.uk/clinical-trials">macmillan.org.uk/clinical-trials</a>



#### How treatment is planned (MDT)

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT). For DCIS, this includes:

- a surgeon, who specialises in breast surgery
- a cancer doctor, who specialises in radiotherapy and hormonal therapy - they are sometimes called oncologists
- a specialist nurse, who gives information and support
- a radiologist, who specialises in x-rays and scans
- a pathologist, who specialises in studying tissue samples and cells.

The MDT may also include other healthcare professionals, such as a physiotherapist, a research nurse, a psychologist, a plastic surgeon, a social worker and a counsellor.

The MDT will look at many factors to help decide which treatments are likely to work best for you. These include:

- the stage and grade of the cancer
- whether the cancer cells have hormone receptors or HER2 receptors
- · your general health.

After the MDT meeting, your cancer doctor or breast care nurse will talk to you about the treatment options. It can help to write down your questions before you meet with them. You can decide together on the best treatment plan for you.

"Specialist nurses are your constant during your journey through cancer. It really doesn't matter what you ask them, how stupid you may feel the question is, or how many times you ring them with yet another query. They are there in the morning when you arrive for your operation and see you after whenever they can. ,,

Helen, diagnosed with DCIS



#### **Making treatment decisions**

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

You may worry about having treatment for a condition that is not life-threatening. But it is important to stop DCIS from becoming invasive breast cancer.

It is important to think about what is right for you. DCIS does not usually need to be treated urgently. So you can take time to think about your options. Talk to your doctor or nurse if you have any questions.

#### Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

#### **Second opinion**

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/secondnoinigo



# Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by a <u>cancer registry</u>.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at <a href="macmillan.org.uk/cancerregistry">macmillan.org.uk/cancerregistry</a>



# Treating DCIS

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## **Surgery for DCIS**

Surgery is the main treatment for DCIS. The operation you have depends on:

- the size of the DCIS
- the position of the DCIS
- what you prefer.

Your surgeon and breast care nurse will talk to you about your options. You may be asked to decide which operation you have.

Your surgeon may recommend breast-conserving surgery. This aims to remove the DCIS safely, but keep as much of the breast tissue and breast shape as possible. This operation is also called a wide local excision (WLE) or lumpectomy. If you have breast-conserving surgery, you may have radiotherapy afterwards. This is to reduce the risk of cancer coming back in the same area.

For some women with DCIS, surgeons may recommend having the whole breast removed. This is called a mastectomy. You can usually choose to have breast reconstruction at the same time as a mastectomy. Or you can have it later. Breast reconstruction is making a new breast shape. Having breast reconstruction is your choice. You may decide not to have it at all. Some women decide to wear a false breast instead. This is called a prosthesis. We have more information about breast prostheses.

#### Wide local excision (breast-conserving surgery)

Your surgeon may suggest having a wide local excision (WLE). This keeps as much of the breast tissue and breast shape as possible. It is sometimes called a lumpectomy.

During a WLE operation, the surgeon removes the DCIS and some normal-looking tissue around it. This is called the margin.

Before the operation, a doctor inserts a fine wire or marker through the skin into the areas of DCIS. This is called wire localisation. The wire or marker is secured to your chest with tape or a dressing. The doctor uses an ultrasound or x-ray to help place the marker so that it marks the area to be removed. When the surgeon does the operation, they can also use x-ray or ultrasound to help them find the right area more easily. During the operation, the surgeon removes the wire along with the areas of DCIS.

You may have a magnetic seed injected into the DCIS instead of having wire localisation. The surgeon uses a handheld machine that can detect the seed and areas of DCIS. Your cancer doctor or breast care nurse can explain more about using magnetic seeds to mark areas of DCIS.

If a large area of DCIS is removed, the breast will be smaller than before. If this happens, the surgeon can reduce the size of your other breast. This can help make your breasts look similar in size.

#### Radiotherapy after breast-conserving surgery

After a WLE, you may be advised to have radiotherapy. This is to reduce the risk of:

- DCIS coming back
- an invasive cancer developing.

You are usually offered radiotherapy if the DCIS is high-grade or if you have larger areas of it. If the area of DCIS is very small and lowor intermediate-grade, you may only need a WLE.

Having a WLE and radiotherapy is as effective at treating DCIS as having a mastectomy.

#### **Clear margins**

After a WLE, a pathologist looks at the tissue that has been removed under a microscope. A pathologist is someone who specialises in looking at tissue samples and cells under a microscope. They check the area around the cancer. This is called the margin. If they find DCIS or cancer cells close to the edges, you will need another operation to remove more tissue. If the margins are clear, this reduces the risk of DCIS coming back or invasive cancer developing.

If your surgeon does not think another WLE is likely to be successful, they will usually recommend a mastectomy. If you have a mastectomy, you will usually also be offered breast reconstruction.

#### Removing the breast (mastectomy)

Breast surgeons will usually try to do an operation that means you can keep your breast. But sometimes they recommend removing the whole breast. This is called a mastectomy. This may be when the DCIS is:

- large in proportion to the rest of your breast
- in more than 1 part of the breast and the affected areas are large.

In these situations, removing enough breast tissue to make sure all the DCIS is removed would not give an acceptable appearance. Your surgeon and breast care nurse will talk to you about your options.

Before a mastectomy, your surgeon may talk to you about removing a small sample of lymph nodes from your armpit. This is called a <u>sentinel</u> lymph node biopsy. It checks for cancer cells in the lymph nodes. Your surgeon or breast care nurse will also talk to you about breast reconstruction.

#### **Breast reconstruction**

If you are having a mastectomy, your surgeon will usually ask if you want a new breast shape made at the same time. This is called an immediate breast reconstruction. You can choose to delay breast reconstruction. Or you may decide not to have it at all. It depends on what is right for you.

If you decide not to have an immediate reconstruction, you can change your mind and have reconstruction later. But if you think you may want reconstruction in the future, it is best to mention this before you have a mastectomy.

Breast reconstruction is specialised surgery. It is usually done by a plastic surgeon or an oncoplastic surgeon. They are experts in breast cancer surgery and reconstruction. There are different ways of doing breast reconstruction. A new breast shape can be made using:

- a silicone implant
- your own tissue taken from another part of your body, such as the back or tummy
- a combination of an implant and your own tissue.

If you have larger breasts and a larger area of DCIS, you can have the DCIS removed and the breast reshaped. This called therapeutic mammoplasty.

There is a higher risk of short-term problems after breast reconstruction. But usually you only need 1 operation. Most people are happy with the result. You surgeon and breast care nurses will usually talk to you about how you feel about your reconstruction.

Your surgeon and breast care nurse will tell you more about the types of breast reconstruction that are suitable for you.

"I wouldn't open the front door without having my padding or false breast in place. I have subsequently had a reconstruction and am much more confident about my body now. "

Helen, diagnosed with DCIS



#### Choice of treatment

A WLE and a mastectomy work equally well for treating DCIS. This means your surgeon and breast care nurse may ask you to decide which type of surgery you feel is right for you.

Your surgeon and nurse can explain what is involved and any possible side effects of each treatment. They will help you decide on the treatment that is best for you.

If DCIS is large, or in more than 1 area, your surgeon will recommend a mastectomy.

Having breast surgery can affect many areas of your life, including your body image, sex life and relationships. It is important to take your time and have all the information you need to make the right decision.

It is helpful to think about the possible advantages and disadvantages of each type of surgery before making a decision.

# **Breast-conserving surgery** and radiotherapy

### **Advantages**

- It aims to keep most of your breast tissue and a good breast shape.
- You usually recover faster than after a mastectomy, and have a lower risk of complications.
- It may be less likely to affect your sex life and relationships.

### **Disadvantages**

- You may need more than 1 operation to get clear margins.
- You may need radiotherapy after surgery. Some people will also need radiotherapy after a mastectomy.
- Radiotherapy has short-term side effects. Some people may have long-term side effects.

### Mastectomy

### **Advantages**

- You may not need radiotherapy after a mastectomy. But some people will need it. Ask your cancer doctor about this.
- Even though a WLE and a mastectomy work equally well, you may feel less worried after a mastectomy. This is because the breast tissue has been removed.

### **Disadvantages**

- You lose your breast permanently.
- It usually takes longer to recover after having a mastectomy, and there is a slightly higher risk of complications.
- It changes your appearance. This may affect your confidence, sex life and relationships.
- If you want breast reconstruction, you will need a longer operation and possibly more surgery. Breast reconstruction is usually more than 1 operation. But reconstruction may help to reduce other disadvantages.

Your surgeon and breast care nurse can answer any questions you may have and tell you what to expect. They may be able to show you photographs of others who have had surgery.

You may find it helpful to talk to others who have had the surgery. Your nurse may know whether there is a local support group, where you can talk to someone who has had a similar operation.

You may also be able to find people in a similar situation through our Online Community - visit community.macmillan.org.uk

Breast Cancer Now also has an online forum - visit forum. breastcancernow.org.

## Sentinel lymph node biopsy (SLNB)

A sentinel lymph node biopsy (SLNB) is a way of checking lymph nodes in the armpit. The lymph nodes most likely to have cancer cells are called the sentinel lymph nodes. These are where lymph fluid first drains to from the breast area.

You will only have an SLNB if you are having a mastectomy. It is done during the operation. This is because sometimes when the breast is removed, it is found to have invasive cancer. In this case, the lymph nodes need to be checked for cancer cells. Having an SLNB during a mastectomy means you do not need a second operation to check the lymph nodes. People having a WLE do not usually have an SLNB.

During an SLNB, surgeons remove a small number of lymph nodes (usually 1 to 3). This reduces the risk of side effects afterwards. These include swelling (lymphoedema) of the arm and stiffness of the arm and shoulder.

If there are no cancer cells in the sentinel nodes, you will not need any further treatment to the lymph nodes.

If cancer cells are found in the sentinel nodes, your cancer doctor will talk to you about whether you need further treatment. You may be offered another operation to remove the remaining lymph nodes. Some people have <u>radiotherapy</u> to the remaining nodes instead of more surgery.

In some hospitals, the sentinel nodes can be checked for cancer cells during your operation. This means if more lymph nodes need to be removed, it can be done during the same operation.

### How an SLNB is done

Before removing the sentinel nodes, the surgeon needs to check which nodes they are.

Before or during the SLNB, you have an injection of radioactive liquid into your breast tissue. The amount used is harmless. During the SLNB, the surgeon uses a handheld machine to find the nodes that have picked up the radioactive liquid. The surgeon may also inject a blue dye into your breast tissue during the SLNB. The dye stains the nodes blue. The sentinel nodes are the nodes that pick up the radioactive liquid or become blue first.

The surgeon can then remove the sentinel nodes. These are tested to see if they have cancer cells in them.

#### Other ways to find sentinel nodes

Some people have their sentinel nodes detected using a magnetic tracer. The magnetic tracer is a liquid containing tiny iron particles. It is injected into the breast, where it is absorbed by the lymph vessels and sentinel nodes. A doctor or nurse can then use a magnetic probe to detect the sentinel nodes. Your doctor or nurse can explain more about magnetic tracers.

# **Before your operation**

Before your operation, you may go to a pre-operative assessment clinic. At the clinic, you may have tests to check your general health. These may include:

- blood tests
- a chest x-ray
- a recording of your heart (ECG).

Your surgeon or breast care nurse will talk to you about how your breast will look after your surgery. They may show you photographs of other people who have had surgery for breast cancer. They may also put you in contact with someone who has had the same operation. Or you can contact a local support group or Breast Cancer Now.

You will usually go into hospital on the day of your operation. You will meet the doctor who gives you the anaesthetic. They are called an anaesthetist. The nurses may give you elastic stockings to wear during and after the operation. These are called TED stockings. They help prevent blood clots.

# After your operation

Your recovery after surgery will depend on the type of operation you have.

After surgery for DCIS, you can usually go home the same day, or the following day.

If you have breast reconstruction at the same time as a mastectomy, you will stay in hospital for longer. This will depend on the type of reconstruction you have.

Your healthcare team will encourage you to start moving around as soon as possible after your operation. This can help reduce the risk of problems that can happen after surgery.

#### Your wound

You will usually have a dressing covering your wound. This may not be removed for the first few days after your operation. Before you go home, the nurses will tell you how to look after it.

After the operation, it is common to have some swelling and bruising around the wound. This should improve after a few weeks. If it does not, tell your breast care nurse. If you had an SLNB, you may see the blue dye in your skin for a few weeks or months. This is normal.

How long it takes for the wound to heal depends on the operation you had. Your wound may be closed with glue or stitches that dissolve. These do not need to be removed. If you do not have stitches that dissolve, they are usually removed 7 to 10 days after your operation. You can arrange this with your practice or district nurse at your GP surgery. Or it may happen at your <u>outpatient appointment</u>.

### **Drains**

You may have a long, thin plastic drainage tube coming from your wound. This is attached to a drainage bag or bottle. Fluid from the wound drains into the bag or bottle.

The tube is usually left in for a few days. You can go home with it still in place. A practice nurse or a district nurse may check and remove it when you are at home. Or you might have it checked and removed at the hospital.

#### Pain

You will probably have some pain or discomfort around the wound. If you had lymph nodes removed, you may also have some pain or discomfort in your armpit.

It can help to take painkillers regularly until the pain starts to improve. This usually takes a few days. The nurses on the hospital ward will usually give you the painkiller to take. If you had a mastectomy, you may need painkillers for 1 or 2 weeks. Tell your cancer doctor or breast care nurse if the painkillers are not helping. They may be able to prescribe different ones for you to try.

## Possible problems after surgery

### Wound infection

Signs of infection can include:

- warmth around the wound
- redness around the wound
- swelling around the wound or discharge coming from it
- · feeling unwell with a fever.

Tell your breast care nurse, cancer doctor or GP if you get any of these symptoms, even after you go home.

### Fluid collecting around the wound (seroma)

A seroma is a soft bulge or swelling around the wound or very close to it. It is caused by a build-up of fluid. It usually goes away within a few weeks. Talk to your surgeon or breast care nurse if the swelling does not go away. They may drain the fluid with a needle and syringe. This may cause some discomfort when it is being done. And it may need to be repeated if the fluid builds up again.

### Stiff shoulder or arm

If you had a mastectomy or lymph nodes removed, your shoulder or arm may feel sore or stiff.

A physiotherapist or nurse will show you some arm exercises to do. These will help improve the movement in your shoulder and arm. They will also reduce the risk of long-term problems. You should start the exercises the day after your operation and slowly build up what you do. It is important to keep doing them until you can move your arm as well as you could before your operation.

Breast Cancer Now has a leaflet about these exercises.

### Numbness and tingling in the upper arm

You may have numbness or a tingling feeling in your upper arm. This is more likely if you had all the lymph nodes in your armpit removed.

Numbness and tingling in the upper arm is caused by swelling and damage to the nerves in your breast and armpit. This can happen during or after the operation. It may slowly improve over a few months, but numbness can sometimes be permanent. Talk to your surgeon or nurse if you are worried.



## Coping with a changed appearance

The first time you look at your breast or chest after surgery you may want to have someone with you. Or you might prefer to be alone. Your breast care nurse will talk to you about this and help support you.

At first, the area may look swollen and bruised. But this will settle in a few weeks. In time, the scar will flatten and fade.

If you normally wear a bra, wearing a supportive crop top might feel more comfortable until the swelling goes down. You will also need to wear a supportive top or bra in hospital after surgery and when at home. This can help to protect the breast and reduce bruising. If you are not comfortable wearing either of these, ask for some advice from your breast care nurse. They can tell you about the best way to support the breast.

Changes to your appearance can cause concerns about your body image. This is the picture in your mind of how your body looks and works. These concerns can make you feel less confident. This may also affect your sex life. You may find that breast reconstruction can help give you back your confidence. You may find our booklet <u>Body image</u> and cancer helpful.

It is not common for men, or other people assigned male at birth, to have reconstruction of their chest. This is because current chest implants do not make a very realistic chest shape. But it may be possible to have tattoos or reconstruction of your nipple. You can ask your breast care nurse or surgeon whether this might be suitable for you.

#### **Scars**

Before your operation, your surgeon or nurse will explain where the scars will be.

Scars from breast-conserving surgery are usually small. But this depends on the amount of tissue removed. The scars may be in the area where the cancer was, or a short distance away. This depends on where the surgeon makes the cut. Your surgeon will try to make any scars as small as possible so they are less noticeable.

If you have a mastectomy, the scar will be across the skin of the chest. It may go up into the armpit. If you have surgery to the lymph nodes, the scar will be in the armpit. It should not be noticeable from the front.

The scar will be firm and slightly raised. Over time, it will flatten and fade. If you have pale skin, your scar will be red straight after your operation. If you have black or brown skin, it will be darker. Everyone's skin heals differently. Scars can take longer to fade if you have black or brown skin, or fair, freckled skin. This means they may be more noticeable for longer.

If you are worried about scars, talk to your nurse or surgeon.

### **Breast prosthesis**

If you do not have breast reconstruction during a mastectomy, your breast care nurse will give you a prosthesis. This is a false breast. It is soft and is often called a cumfie or softie. You can wear it inside a bra. You can wear it straight after your operation.

When your wound has healed, you can choose a permanent prosthesis made of soft plastic called silicone. This usually happens about 6 weeks after your operation. The permanent prothesis will be matched to the size and shape of your other breast and your skin colour. You may find your confidence gradually improves as you get used to it.

You can get different types of prosthesis from the NHS. Breast Cancer Now can also give you a list of suppliers.

## When you get home

Your recovery will depend on the type of operation you have. You may need to avoid lifting or carrying anything heavy for a few weeks.

If you drive, contact your car insurance company to let them know you have had an operation. Most people are ready to drive about 4 weeks after their operation. But some insurance policies give specific time limits for not driving after surgery. Do not drive unless you feel in full control of the car.

When you are home, it is important to follow the advice you were given by your breast care nurse. You should keep doing the exercises you were given in hospital and try do some light exercise, such as walking. This can help to build up your energy so you can gradually get back to your normal activities.

# **Outpatient appointment and results**

You will have an appointment with your surgeon and breast care nurse. This will be at the outpatient clinic. They will check that the wound is healing properly. They will also tell you about the tissue that was removed during surgery (pathology) and the grade of the DCIS.

If you have had a wide local excision (WLE), your surgeon will tell you whether the margins around the DCIS are clear. If the margins are not clear, you may need another operation.

Sometimes a small area of invasive cancer is found with the DCIS. Although this can be distressing news, it is usually very early breast cancer, which can be treated successfully.

If you have had a WLE and invasive cancer is found, you may need a second operation to do a sentinel lymph node biopsy. If you have had a mastectomy, you will already have had this.

Your surgeon and breast care nurse will also talk to you about any further treatment you may need. This may include radiotherapy or hormonal therapy.

# Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given, while doing as little harm as possible to normal cells.

Radiotherapy helps to reduce the risk of DCIS coming back in the area it is given. You have it after surgery to destroy any remaining DCIS cells. It also helps reduce the risk of invasive cancer developing.

After breast-conserving surgery, your cancer doctor will usually recommend you have radiotherapy to the breast if the DCIS is high-grade. It is sometimes given for larger intermediate-grade DCIS. You will not usually be recommended radiotherapy if the DCIS is low-grade. You usually start radiotherapy about 4 to 6 weeks after surgery.

Your cancer doctor and breast care nurse will explain why radiotherapy is recommended for you. It is important to talk to them about any concerns you have.

# Planning your radiotherapy

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. Tell the radiographer if you are worried about them or already have a tattoo in the area to be treated.

# Having radiotherapy

You have the radiotherapy as an outpatient. It is usually given using equipment that looks like a large x-ray machine. This is called external beam radiotherapy (EBRT) or external radiotherapy. The person who operates the machine is called a therapy radiographer. They will give you information and support during your treatment.

You usually have radiotherapy as a series of short daily treatments. Each treatment is a called or a session. You usually have sessions from Monday to Friday, over 1 to 3 weeks. Some people may be offered more treatment to the area where the DCIS was. This is called a radiotherapy boost. Your cancer doctor will tell you how many treatments you will need.

If you have radiotherapy to your left breast, you will usually be asked to take a deep breath and hold it briefly. This is called deep inspiration breath hold (DIBH). You do this at each of your planning and treatment sessions. DIBH helps protect your heart during radiotherapy treatment to your left side. Your heart is behind the left side of your chest. DIBH moves the heart away from the area being treated. It also keeps you still and reduces the risk of late effects. A website called respire.org.uk explains more about DIBH.

You may have intensity-modulated radiotherapy (IMRT). This is another type of external radiotherapy. It shapes the radiotherapy beams and allows the radiographer to give different doses of radiotherapy to different areas. This means you have lower doses of radiotherapy to healthy tissue surrounding the tumour.

External radiotherapy does not make you radioactive. After your treatment, it is safe for you to be with other people, including children.

### Treatment sessions

Your radiographer will explain what happens during treatment. At the beginning of each session, they make sure you are in the correct position. Usually, you lie with your arms above your head. If your muscles and shoulder feel stiff or painful, a physiotherapist can show you exercises that may help.

When you are in the correct position, the radiographer leaves the room and the treatment starts. The treatment is not painful and only takes a few minutes.

The radiographers can see and hear you from outside the room. You can usually talk to them through an intercom, if you need to.

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions.

If your muscles and shoulder feel stiff or painful, a physiotherapist can show you exercises that may help.

# Side effects of radiotherapy

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. Sometimes side effects get worse for a time during and after you have finished radiotherapy before they get better.

If you are having the radiotherapy over 1 week, sometimes the side effects may not start for 2 to 3 weeks after treatment.

Your cancer doctor, breast care nurse or radiographer will tell you what to expect. They will give you advice on what you can do to manage side effects. If you have any new side effects or if side effects get worse, tell them straight away.

### Skin irritation

If you have white or pale skin, the treated area may get red, dry and itchy. If you have black or brown skin, the treated area may get darker, dry and itchy. Your nurse or radiographer will give you advice on looking after your skin. If it becomes sore and flaky, your doctor can prescribe creams or dressings to help this.

Skin reactions usually get worse after treatment for a few weeks. But they slowly start to improve 2 weeks after radiotherapy ends.

Here are some tips for skin reactions:

- Do not put anything on your skin in the treated area without checking with your cancer doctor, nurse or radiographer.
- Have cool or warm showers or baths. Turn away from shower spray to protect the treated area.
- Avoid shaving, waxing or using epilators on your underarm on the affected side.

- Gently pat the area dry with a soft towel do not rub.
- Wear loose clothing. This is less likely to irritate your skin.
- Avoiding swimming if your skin is irritated.

You need to avoid exposing the treated area to the sun during radiotherapy and after treatment finishes. Use suncream with a sun protection factor (SPF) of at least 30.

#### **Tiredness**

This is a common side effect that may last for a few weeks or months after treatment. Studies show that exercise can help to manage tiredness caused by treatment. Try to get enough rest and pace yourself. But it is important to balance this with some physical activity, such as going for short walks. This can give you more energy.

### Aches and swelling

You may have a dull ache in the treated area. Or you may get shooting pains that last for a few seconds or minutes. You may also notice that the area becomes swollen. These effects usually improve after treatment. But you may still have some aches and pains in the area after treatment ends. The area can sometimes stay a little swollen after treatment.

## Late effects of radiotherapy

Radiotherapy to the breast may cause side effects that happen months or years after radiotherapy. These are called late effects. Newer ways of having radiotherapy are helping reduce the risk of late effects. If you are worried about late effects, talk to your cancer doctor, breast care nurse or radiographer.

The most common late effect is a change in how the breast or chest area looks and feels.

Radiotherapy can damage small blood vessels in the skin. This can cause red, spidery marks to show. These are called telangiectasia. They may be more common if you had boost doses of radiotherapy.

After radiotherapy, your breast may feel firmer and shrink slightly in size. If your breast is noticeably smaller, you can have surgery to reduce the size of your other breast. If you had breast reconstruction using an implant before radiotherapy, you may need to have the implant replaced.

You may find the treated area sore or uncomfortable for some time. This usually improves over years. It is not uncommon to get pain in the muscle or ribs at the edge of the breast if you overdo things. Very rarely, radiotherapy may cause lung problems or problems with the ribs.

If you have radiotherapy to the left breast, very rarely it can cause heart problems. Tell your cancer doctor, nurse or radiographer if you notice any problems with your breathing, or have any pain in the chest area.

We have more information in our booklet Managing the late effects of breast cancer treatment.



# **Hormonal therapy** for DCIS

Hormones help control how cells grow and what they do in the body. The hormone oestrogen can encourage some breast cancers to grow. This may also happen with the hormone progesterone.

Hormonal therapy reduces the amount of oestrogen in the body or stops it attaching to cancer cells. It only works for breast cancer that is oestrogen receptor positive (ER positive). Hormonal therapy is also called endocrine therapy.

Hormonal therapy is commonly used to treat invasive breast cancer. This is because it reduces the risk of breast cancer coming back. Hormonal therapy can also reduce the risk of DCIS coming back. But the benefits may not always outweigh the side effects.

Your cancer doctor will explain the possible benefits and disadvantages of hormonal therapy in your situation. The type of hormonal therapy you have depends on whether you have been through the menopause.

# Taking hormonal therapy

Hormonal therapy drugs used for DCIS include tamoxifen and the aromatase inhibitors letrozole, anastrozole and exemestane.

#### **Tamoxifen**

You may have tamoxifen to help reduce the risk of ER positive DCIS coming back. It can also reduce the risk of invasive cancer in both breasts.

You may have it whether you have been through the menopause or not. You take it as a tablet daily. This is usually for 5 years.

The side effects are similar to the effects of the menopause. They include:

- hot flushes and sweats
- · weight gain
- tiredness.

If you have been through the menopause, tamoxifen can slightly increase the risk of womb cancer. It can also increase the risk of developing a blood clot. Although this sounds scary, it is very rare. Blood clots are usually found very early when they can be treated successfully.

If you are struggling with the side effects of tamoxifen, let your cancer doctor or nurse know. They can give you advice on how to manage these. Recent studies have shown that a lower dose of tamoxifen can still help to reduce the chances of DCIS coming back or invasive breast cancer developing. Your doctor can tell you if a lower dose is suitable for your situation.

### **Aromatase inhibitors (Als)**

Aromatase inhibitors (Als) are the main hormonal therapy drugs given if you have invasive breast cancer after the menopause. They stop oestrogen being made in the fatty tissue. Like tamoxifen, these drugs only work if you have ER positive DCIS.

Als may reduce the risk of:

- DCIS coming back
- developing invasive cancer in both breasts.

Your cancer doctor or breast care nurse can tell you more about any clinical trials that you may be suitable for. We have more information about clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Your doctor may prescribe an AI such as:

- anastrozole
- exemestane
- letrozole.

You take these drugs as a tablet daily. Side effects can include:

- tiredness
- joint and muscle pain
- hot flushes.





# After treatment for DCIS

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# Follow-up after treatment for DCIS

After treatment, you will have yearly mammograms for 5 years. If you had a mastectomy, the mammogram will be of your other breast.

After 5 years, if you are 50 or over, you usually have mammograms through the NHS breast screening programmes. Younger women usually continue to have yearly mammograms after the first 5 years, until they reach 50.

Instead of regular appointments, your breast care nurse may give you information about what to look out for. They will give you contact numbers, and ask you to contact them or your cancer doctor if there is anything you are worried about. This includes any side effects you may still be having. If you had <u>breast reconstruction</u>, you can tell them any worries you may have about your new breast shape.

You may have your follow-up appointments at a nurse-led clinic. You will still go to a cancer doctor if something needs to be checked further.

It is natural to feel anxious after treatment ends. It can help to get support from family, friends or a helpful organisation. You can also contact our cancer support specialists on 0808 808 00 00.

### Be aware of changes

You will have yearly mammograms, but it is still a good idea to know what is now normal for you. Your treated breast will look and feel different. This will depend on the treatment you had.

Your nurse can tell you what you to expect and what to check for. It is also important to be aware of what to look out for in your untreated breast. Possible signs and symptoms of breast cancer include:

- a lump in the breast
- thickening of the skin or tissue of the breast
- dimpling of the skin of the breast
- a lump or swelling in either armpit
- a change in the shape or size of the breast, such as swelling in all or part of the breast
- a nipple turning in (inverted nipple)
- an eczema-like rash on the nipple
- discharge or bleeding from the nipple
- pain or discomfort in the breast that does not go away this is rare.

If you notice anything unusual between appointments, contact your cancer doctor or breast care nurse straight away.

### If DCIS comes back

After treatment, the risk of DCIS coming back or getting invasive breast cancer is reduced. Any new problems can usually be found very early during your yearly mammograms.

Your doctor will usually advise you to have a mastectomy if:

- DCIS comes back in the treated breast
- pre-cancerous cells are found in the treated breast
- an invasive cancer develops in the treated breast.

If you have not already had radiotherapy, it might be possible to remove the area with surgery and then have radiotherapy. Treatment is usually very successful if DCIS comes back or an early invasive breast cancer develops in the treated breast.



# Effects after treatment

After treatment, you will probably want to get back to doing the things you did before diagnosis. But you may still be coping with some side effects of treatment and your feelings. It is important to try not to expect too much of yourself. It can often take several months to recover from the effects of treatment.

It is important to talk about any concerns or questions you have with your cancer doctor and breast care nurse. After treatment, you may want to know:

- what to expect
- · whether there is anything you should avoid
- how to make the most of your health
- where to get support.

### Sex life

DCIS and its treatments and side effects may affect your sex life and how you feel about yourself (body image).

Difficulties often slowly improve after treatment, but it can sometimes take longer. You may feel insecure and worry about your current or future relationships.

If you have a partner, you may feel insecure about whether they will still find you sexually attractive. It can help to try to talk about it with them. You may both need some time to adjust.

Let your doctor or nurse know if any difficulties with your sex life do not improve. They may be able to reassure you or offer further help and support. If you feel uncomfortable talking to your doctor or nurse, you can call us on 0808 808 00 00.

Some people may find it helpful to talk to a sex therapist. You can contact a therapist through the College of Sexual and Relationship Therapists.

We have more information in our booklets Cancer and your sex life and Body image and cancer.

### Contraception

Your cancer doctor or nurse will usually advise you not to use contraception that contains hormones. This includes the pill or implants that release hormones. Your GP can give you advice about suitable methods of contraception. These may include:

- coils (intra-uterine devices) that do not contain hormones
- barrier methods such as condoms
- diaphragms or caps.

#### Mirena® coil

The Mirena® coil works by releasing a small amount of a hormonal medicine into the womb. The medicine is called levonorgestrel. It is an artificial type of progesterone. Doctors are unsure how much of it reaches other parts of the body after it has been released into the womb

Studies have tried to find out if the Mirena® coil could cause cancers that depend on hormones to grow. The results have been mixed. But there is currently no strong evidence to show that the Mirena® coil encourages these types of cancer to grow. Because it contains progesterone, it is not usually recommended for people who have had cancers that depend on hormones to grow. This includes breast cancer.

If you are concerned, you can talk to your GP or specialist about what contraception is best for you.

### Menopausal symptoms

Some treatments for DCIS may cause menopausal symptoms. Doctors do not recommend hormone replacement therapy (HRT). This is because it contains oestrogen, which could encourage breast cancer cells to grow.

## Lymphoedema

Lymphoedema is a swelling of the arm or hand on the side that you had treatment. Some people also have swelling in the breast or chest area. It sometimes happens after surgery or radiotherapy to the lymph nodes in the armpit. Most people with DCIS do not have surgery or radiotherapy to the armpit. Some people with DCIS have a sentinel <u>lymph node biopsy</u>. If you had this, your risk of lymphoedema is small.

There are things you can do to help reduce your chances of developing lymphoedema. It is important to protect your arm and hand, and to look after the skin in these areas.

If you notice any swelling in your arm, hand or chest, ask your doctor or nurse to check it. The earlier lymphoedema is diagnosed, the easier it is to manage and treat successfully. We have more information in our booklet Understanding lymphoedema.

You can order our booklets and leaflets for free. Visit be.macmillan.org.uk or call us on 0808 808 00 00.



# Well-being and recovery

After treatment for DCIS, you may choose to make some positive lifestyle changes. You may have already had a healthy lifestyle before DCIS. But you may be more focused on making the most of your health.

# Eat well and keep to a healthy weight

Try to keep to a healthy weight. Being overweight after the menopause can increase the risk of breast cancer. Keeping to a healthy weight also reduces the risk of some other cancers, heart problems and other illnesses such as diabetes. Try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less saturated fat and sugar
- be more physically active.

# Be physically active

Being physically active helps keep your weight healthy and can reduce stress and tiredness. It helps keep your bones strong and your heart healthy.

# Stop smoking

If you smoke, stopping is one of the healthiest decisions you can make. Smoking increases your risk of osteoporosis, and is a major risk factor for smoking-related cancers and heart disease.

# Stick to sensible-drinking guidelines

It is best to limit alcohol intake. Current NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in 1 week
- spread the alcohol units you drink in 1 week over 3 or more days
- try to have several alcohol-free days every week.

#### A unit of alcohol is:

- half a pint (285ml) of ordinary-strength beer, lager or cider
- 1 small glass (125ml) of wine
- a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at drinkaware.co.uk

# Try to reduce stress in your life

Being diagnosed with breast cancer can be stressful. One way of coping with stress is to make time to relax. This could include:

- going for a walk
- having a meal with family or friends
- listening to music or watching a film
- trying activities such as yoga, or relaxation techniques to control breathing
- being more physically active and looking after your well-being
- talking to someone about how you feel.

# **Your feelings**

Although DCIS is not life-threatening, you may still have difficult feelings to cope with. As you recover and get back to your everyday life, these usually get easier to deal with. The type of treatment you had will affect how you feel. You may have changes in your appearance or have to cope with side effects.

Our booklet How are you feeling? The emotional effects of cancer has tips for managing feelings.

Talking to family and friends about your feelings usually helps. You might find our booklet Talking about cancer helpful. You can get advice and support from your cancer doctor or specialist nurse too. Or you can ask them to refer you to a trained counsellor. Our cancer support specialists on 0808 808 00 00 can tell you more.

### Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. We can give you information about support groups in the UK.

# **Online support**

Many people get support on the internet. This may include online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experience, ask questions, and get and give advice based on your breast cancer experience.

Our Online Community is a social networking site where you can talk to people, write blogs, make friends and join support groups.

# Talking to children

Deciding what to tell children can be difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong. Sometimes their fears can be worse than the reality. How much you tell children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information and gradually tell them more to build up a picture.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

When I had the surgery, I couldn't do anything for 2 months. I was heavily reliant on my husband and my friends to take me everywhere and do everything. It put immense pressure on him but he dealt with it really well.

Katy, diagnosed with DCIS



# Financial help and work

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# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online.

#### Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

### **Macmillan Grants**

Macmillan Grants are small, one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills. you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on 0808 808 00 00 or visit macmillan.org.uk/grants

#### Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on 0808 808 00 00.

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community



You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work





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# **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

#### Order what you need

You may want to order more booklets or leaflets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

#### Online information

All our information is also available online at macmillan.org.uk/ information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

#### Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets

- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on 0808 808 00 00.

#### The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

#### Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

#### **Macmillan Support Line**

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on 0808 808 00 00. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/ talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

#### **Macmillan Information and Support centres**

Our Information and Support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at <u>macmillan.org.uk/informationcentres</u> or call us on 0808 808 00 00.

#### Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <a href="mailto:macmillan.org.uk/financialsupport">macmillan.org.uk/financialsupport</a> to find out more about how we can help you with your finances.

#### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

#### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on 0808 808 00 00 to find out more about Macmillan Grants.

#### Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

#### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on 0808 808 00 00 to speak to a work support adviser.

#### Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

#### **Support groups**

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting <a href="mailto:macmillan.org.uk/selfhelpandsupport">macmillan.org.uk/selfhelpandsupport</a>

#### **Online Community**

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

#### Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

#### **Breast cancer support organisations**

#### **Breast Cancer Haven**

#### Tel 0757 263 7588

#### www.breastcancerhaven.org.uk

Delivers one-to-one support sessions, healthy eating, exercise and stress reduction classes, and a range of self-help videos and resources. These can be accessed online.

#### **Breast Cancer Now**

#### Helpline **0808 800 6000**

#### www.breastcancernow.org

Provides information and practical and emotional support to people affected by breast cancer. Specialist breast care nurses run the helpline. Also offers a peer support service where anyone affected by breast cancer can be put in touch with a trained supporter who has had personal experience of breast cancer.

#### **Keeping Abreast**

#### Tel 0160 381 9113

#### www.keepingabreast.org.uk

Offers support for people having breast reconstruction. Provides a network of dedicated support groups and online support across the UK.

#### **Lobular Breast Cancer UK**

#### www.lobularbreastcancer.org.uk

Offers support to people living with lobular breast cancer.

#### Respire

#### www.respire.org.uk

Aims to improve the patient experience by helping patients to be prepared for receiving their radiotherapy.

#### **General cancer support organisations**

#### **Asian Women Cancer Group**

#### www.asianwomencancergroup.co.uk

Helps Asian women who have been affected by cancer. Provides emotional support and financial guidance.

#### **Black Women Rising**

#### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **Cancer Black Care**

#### Tel 0208 961 4151

#### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

#### **Cancer Focus Northern Ireland**

#### Helpline 0800 783 3339

#### www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland

#### **Cancer Research UK**

#### Helpline 0808 800 4040

#### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Cancer Support Scotland**

#### Tel 0800 652 4531

#### www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### Maggie's

#### Tel **0300 123 1801**

#### www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

#### **Emotional and mental health support**

#### British Association for Counselling and Psychotherapy (BACP)

#### Tel 0145 588 3300

#### www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

#### **College of Sexual and Relationship Therapists**

#### Tel **0208 106 9635**

#### www.cosrt.org.uk

The professional body for psychosexual and relationship therapists.

You can also search for a qualified counsellor on the 'Find a therapist' page.

#### **Samaritans**

#### Helpline 116 123

#### Email jo@samaritans.org

#### www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

#### Financial support or legal advice and information

#### Advice NI

#### Helpline 0800 915 4604

Provides advice on a variety of issues including financial, legal, housing and employment issues.

#### **Benefit Enquiry Line Northern Ireland**

Helpline 0800 232 1271

Textphone **028 9031 1092** 

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

#### **England**

Helpline **0800 144 8848** www.citizensadvice.org.uk

#### Scotland

Helpline 0800 028 1456 www.cas.org.uk

#### **Wales**

Helpline 0800 702 2020 www.citizensadvice.org.uk/wales

#### **GOV.UK**

#### www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

#### **Money Advice Scotland**

#### www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

#### Unbiased.co.uk

#### Helpline 0800 023 6868

#### www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

#### **LGBT-specific support**

#### LGBT Foundation

#### Tel **0345 330 3030**

#### www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. Has information on various topics including sexual health, relationships, mental health, community groups and events.

#### General health information

#### **Drinkaware**

#### www.drinkaware.co.uk

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

#### **Cancer registries**

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is a cancer registry in each country in the UK. They are run by the following organisations:

#### **England - National Disease Registration Service (NDRS)**

digital.nhs.uk/ndrs/patients

#### Scotland - Public Health Scotland (PHS)

publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/ cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

#### Wales - Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278** phw.nhs.wales/wcisu

#### Northern Ireland - Northern Ireland Cancer Registry (NICR)

Tel 0289 097 6028

gub.ac.uk/research-centres/nicr/AboutUs/Registry

#### Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

#### **Thanks**

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Professor Mike Dixon, Professor of Surgery and Consultant Surgeon.

With thanks to: Dr Russell Burcombe, Clinical Oncologist; Josie Cameron, Breast Advanced Practice Radiographer; Heather Driver, Breast Cancer Clinical Nurse Specialist; Miss Joanna Franks, Breast Consultant and Oncoplastic Surgeon; Claire Herlihy, Breast Cancer Clinical Nurse Specialist; Donna McKeown, Advanced Nurse Practitioner; Sally Shanley, Breast Cancer Clinical Nurse Specialist; Dr Richard Simcock, Consultant Clinical Oncologist and Consultant Medical Adviser, Macmillan; and Debbie Turnbull, Macmillan Breast Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition. and those who shared their stories.

We welcome feedback on our information. If you have any, please contact cancerinformationteam@macmillan.org.uk

#### **Sources**

Below is a sample of the sources used in our DCIS information. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

British Medical Journal (BMJ). Best Practice. Breast cancer in situ. 2020. Update 2023. Available from: <a href="https://bestpractice.bmj.com/topics/">https://bestpractice.bmj.com/topics/</a> en-gb/717?g=w bmj bp [accessed 2023]

ESMO. Early breast cancer clinical practice guidelines for diagnosis. treatment and follow-up. 2019, Vol 30, pp1192-1220. Available from: https://www.esmo.org/quidelines/quidelines-by-topic/breast-cancer/ early-breast-cancer [accessed 2023].

National Institute for Health and Care Excellence (NICE). Early and locally advanced breast cancer: diagnosis and management. 2018. Updated 2023. Available from: https://www.nice.org.uk/guidance/ng101 [accessed 2023].

### Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

### 5 ways you can help someone with cancer

#### 1. Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

#### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### Help someone in your community 3.

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### Raise money 4.

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

#### 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details		Do not let the taxman	
Mr/Mrs/Miss/Oth	ner	keep your money	
Name		Do you pay tax? If so, your gift will be worth 25% more to us -	
Surname		at no extra cost to you. All you	
Address		have to do is tick the box below,	
Postcode		and the tax office will give 25p for every pound you give.	
Phone		I am a UK tax payer and	
Email		I would like Macmillan Cancer	
Please accept my gift of £ (Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support		Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations until I notify you otherwise.	
			OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro
Card number		difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.	
Valid from	Expiry date	Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use	
Issue no	Security number	your details in this way please tick this box. In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.	
Signature		If you would rather donate online go to macmillan.org.uk/donate	
Date / /			







# This booklet is about ductal carcinoma in situ (DCIS). It is for anyone who has been diagnosed with DCIS. There is also information for carers, family members and friends.

DCIS is the earliest form of breast cancer. The booklet talks explains how DCIS may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk** 

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats?
We produce information in audio, interactive PDFs, easy read, Braille, large print and translations.
To order these, visit macmillan.org.uk/otherformats or call our support line.



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