

A practical guide to understanding cancer

# UNDERSTANDING DUCTAL CARCINOMA IN SITU (DCIS)



**'I was so lucky that it was picked up at the screening. If I had to wait until I noticed something, then who knows how things would be different.'**

**Wendy, diagnosed with 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 that breast cancer cells are in the milk ducts, but they haven't spread into (invaded) surrounding breast tissue. There is more information about invasive breast cancer on page 9.

This booklet is for people who have DCIS. We hope it answers some of your questions about diagnosis and treatment, and helps you deal with some of the feelings you may have.

DCIS can occur in both women and men, but it is very rare in men. We have more information for men in our booklet **Understanding breast cancer in men.**

Throughout the booklet we've included comments from women who have had DCIS, which you may find helpful. Some are from the **healthtalk.org** website. Others are from people who have chosen to share their story with us by becoming a Cancer Voice – like Wendy on the cover of this booklet. To find out more, visit **macmillan.org.uk/cancervoices** Some names have been changed.

We can't advise you about the best treatment for yourself. This advice can only come from your doctor, who knows your full medical history.

## Further information

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **[macmillan.org.uk](http://macmillan.org.uk)**

Turn to pages 95–99 for some useful addresses and websites, and to page 100 for some space to write down any notes or questions you have.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

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# THE BREASTS AND DCIS

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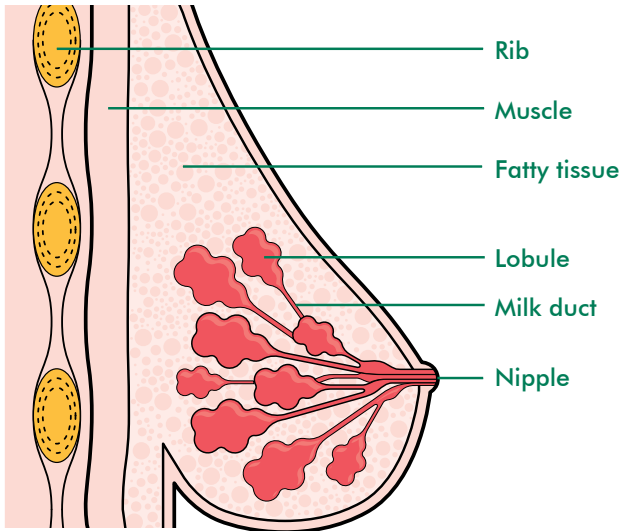
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# The breasts

Breasts are made up of fat, supportive (connective) tissue and glandular tissue containing lobules. The lobules (milk glands) are where breast milk is made. They connect to the nipple by a network of fine tubes called ducts.

The breast tissue extends into the lower armpit (axilla). The armpits also contain a collection of lymph nodes (glands), which are part of the lymphatic system. The lymphatic system protects you from infection and disease. It is a network of lymph glands throughout the body connected by tiny vessels called lymph vessels.

## Side view of the breast



It's common for a woman's breasts to be a different size or shape from each other. They also feel different at different times of the month. For example, just before a woman's period, her breasts may feel lumpy. As a woman gets older, her breasts may change size and shape, and become softer.

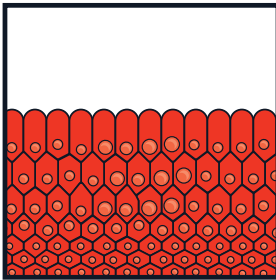


# What is DCIS?

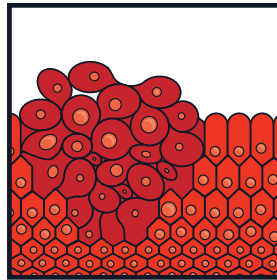
To understand DCIS, it helps to know how cancer usually develops.

The organs and tissues of the body are made up of tiny building blocks called cells. Normally, cells divide in an orderly and controlled way. But if the process gets out of control, the cells carry on dividing and develop into a lump called a tumour. Doctors can tell whether a tumour is benign (non-cancerous) or malignant (cancerous) by removing a piece of tissue (biopsy) and examining a small sample of cells under a microscope.

Normal cells



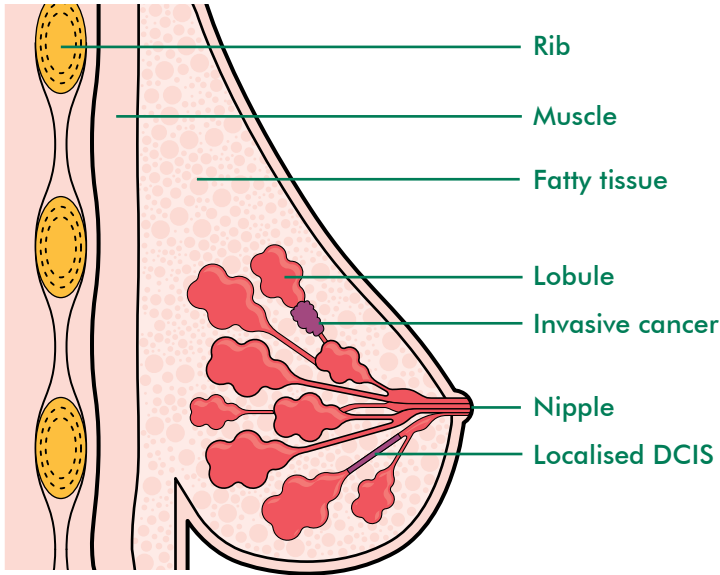
Cells forming a tumour



Breast cancers usually start in the cells that line the lobules and their draining milk ducts (see diagram opposite). The place where DCIS starts is the terminal duct lobular unit. In this booklet, we use the simpler terms lobules and ducts.

In DCIS, the cancer cells are completely contained in the lobules and ducts. The cells haven't broken through the walls of the lobules or ducts or grown into surrounding breast tissue.

## Side view of the breast showing DCIS



DCIS is the earliest possible form of breast cancer. It isn't a life-threatening condition, but treatment is usually recommended.

'DCIS was something I'd never heard of before. Different friends have had different sorts of breast cancers but never DCIS.'

Sue

## DCIS and invasive breast cancer

If DCIS isn't treated, it may over time spread into (invade) the breast tissue surrounding the ducts to become an invasive breast cancer. Not every untreated DCIS will develop into an invasive breast cancer. But breast specialists may advise treating DCIS because it isn't possible to tell for certain which individual cases of DCIS will become an invasive cancer.

Having DCIS means you have a slightly higher risk of getting cancer elsewhere in the same breast or in your other breast. Guidelines recommend that women who have had DCIS have mammograms every year. There's more information about follow-up after DCIS on pages 66–67.



## Risk factors and causes

The risk factors for DCIS and invasive breast cancer are similar. It's not clear exactly what causes breast cancer but different things can increase a woman's risk of developing it. These include:

- **Increasing age** – The risk of DCIS increases with age. It's rare in women under the age of 35.
- **Previous breast cancer and some non-cancerous (benign) breast conditions** – Having one of these can increase the risk.
- **Dense breast tissue** – Women are slightly more likely to develop cancer when the breasts have more glandular and connective tissue, with very little fatty tissue.
- **Not having children** – Women who haven't had children are slightly more likely to develop breast cancer than women who have.
- **Not breastfeeding** – Women who have never breastfed are slightly more at risk than women who have breastfed for more than a year.
- **Early periods or a late menopause** – Women whose periods started before they were 12 or who've had a late menopause (after the age of 50) are at a slightly higher risk.
- **Hormone replacement therapy (HRT)** – This reduces some effects of menopause but can increase the risk of breast cancer. You can talk to your GP about the benefits and possible risks of taking HRT.
- **Lifestyle factors** – Being overweight after the menopause and drinking more than two units of alcohol a day over many years can slightly increase risk. Smoking heavily from a young age can also increase risk.

## Family history and risk

Most women diagnosed with breast cancer don't have any family history of it. Only a very small number of women with breast cancer have a gene that greatly increases the risk of breast cancer. The two genes most often found in hereditary breast cancer are called BRCA1 and BRCA2.

Generally, the chance of breast cancer being hereditary is greater when:

- a number of family members have been diagnosed with breast cancer or related cancers, such as ovarian cancer
- these family members are closely related to you
- these family members were diagnosed at a young age.

## Online risk assessment

Our website has an interactive tool called OPERA (Online Personal Education and Risk Assessment). It asks specific questions about your family history of breast and ovarian cancer. It gives you personalised information and support about your inherited breast cancer risk. OPERA isn't intended to take the place of professional genetic counselling services. If you're concerned about genetic risk, you should still consult your doctor.



You can access OPERA at [macmillan.org.uk/opera](https://macmillan.org.uk/opera)





# DIAGNOSING DCIS

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## How DCIS is diagnosed

Most women with DCIS have no symptoms and the DCIS is found through changes seen on a mammogram. More women are having mammograms as part of the National Breast Screening Programme, so DCIS is now diagnosed much more often than it used to be. One in five breast cancers found by screening in the UK are DCIS.

The NHS Breast Screening Programmes aim to find breast cancer very early so women have the best chance of a cancer being cured. In the UK, women aged 50–70 are invited to attend breast screening every three years. In England, the age range is gradually being extended to include women aged 47–73.

'I would say to all women, please go and take the screening because it saved my life and it could save your life. I know some people are frightened in case they find anything but that's what you want them to do. It's only a few minutes pressure on your breast. It's only ten minutes to go through the whole process and it's a life-saver.'

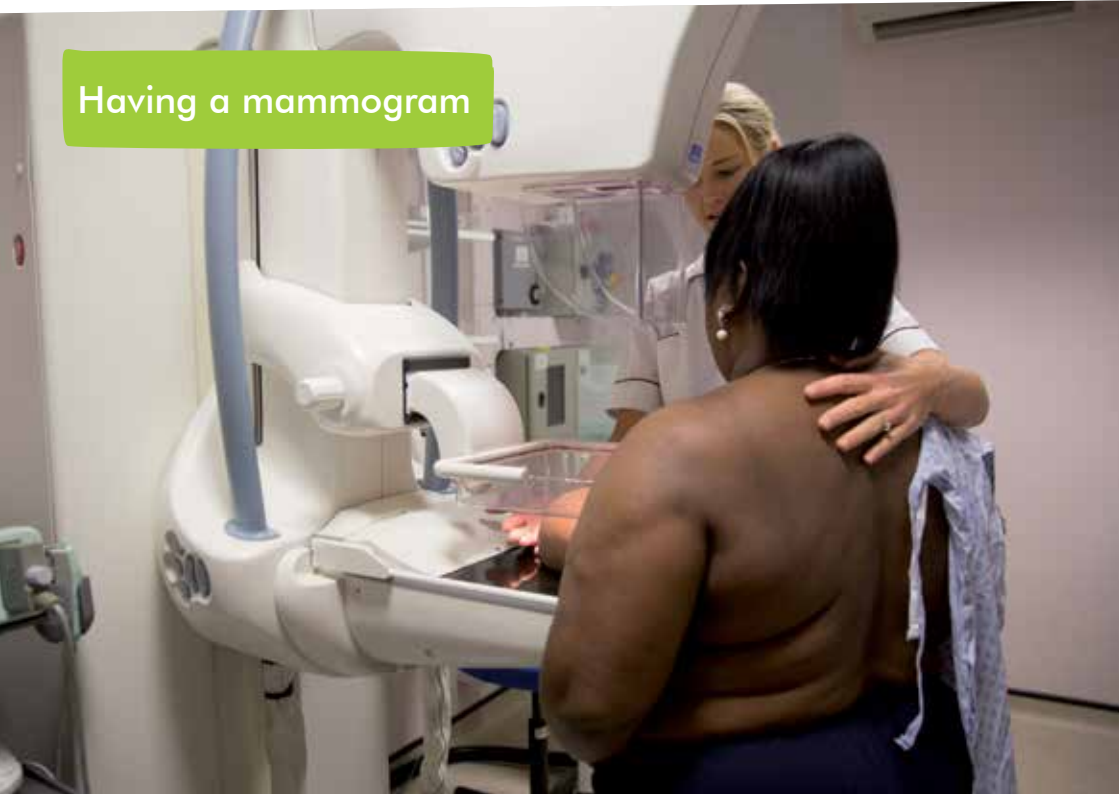
**Jacky**

## Mammogram

A mammogram is a low-dose x-ray of the breast, which can detect changes in the breast tissue.

You will need to undress down to your waist. The radiographer will then position you so that your breast is against the x-ray machine. Your breast will be gently but firmly flattened with a clear, plastic plate. Your breast needs to be held this way to keep it still and to get a clear picture. You might find this uncomfortable or even painful, but this should only last for as long as the mammogram takes. Some women may feel tender in the area for a few days afterwards. Painkillers can help with this.

### Having a mammogram



You will have two x-rays of each breast taken from different angles. Women who have very large breasts might need to have extra x-rays to make sure all the breast tissue is included.

You need to stay still for less than a minute while each mammogram is taken. You can say stop at any time if you feel too uncomfortable. The radiographer carries out many mammograms every day and will try to make you as comfortable as possible.

In younger women, the breast tissue is more dense (has less fat). This makes it difficult to detect any changes on the mammogram.



We have more information about breast screening that we can send you.

'One of my concerns was that if I hadn't gone for this mammogram I wouldn't have known anything because I was always told, like lots of women, that you feel for a lump. There was no lump, there were no problems with the nipple, there was nothing like that at all. I had seen absolutely no difference in my breasts at all.'

**June**

## Symptoms

A small number of women go to their GP with breast symptoms and are referred for a mammogram. These symptoms may be:

- a breast lump
- discomfort or pain in one breast
- fluid (discharge) from the nipple
- a rash or itching on or around the nipple.

## Paget's disease of the breast

Paget's disease is a condition that affects the skin of the nipple. It causes redness, discharge or bleeding and sometimes itching of the nipple and the darker area around it (the areola).

Women who have Paget's disease may have DCIS or an invasive breast cancer.



We can send you more information about Paget's disease.





## Micro-calcification

DCIS usually shows up as an area of tiny specks of calcium, known as micro-calcifications, which collect in the milk ducts and lobules.

Micro-calcifications can't usually be felt and are detected by a mammogram. They are common as women get older and are usually harmless. But in a small number of cases, a group of micro-calcifications in one area (a cluster) can be a sign of DCIS or early breast cancer.

If micro-calcifications are found, you'll usually have a magnified mammogram to examine the area more closely. A radiologist will look at the size, shape and pattern of the calcification.

If your mammograms show possible signs of DCIS, you'll have further tests to find out more. These tests are described next.

## Further tests

If a mammogram shows changes, you will be referred to a breast assessment clinic. The clinic staff will explain why you've been invited back and which tests you need. You might be able to have the tests on the same day, but sometimes you have to come back for further tests.

The clinic staff will let you know how and when you'll get your results. You'll usually be given an appointment to return for your results.

### At the breast assessment clinic

At the clinic, you'll see a specialist doctor or a specialist nurse. They usually ask you if you have had any breast problems or if anyone in your family has had breast cancer. The doctor or nurse will examine your breasts and the lymph nodes under your arm and around your neck. We describe some of the tests you might have over the next few pages.

### Mammogram

You may have more mammograms that focus on the area of DCIS. These can be taken from different angles or can use magnification.

### Breast ultrasound

An ultrasound scan uses sound waves to build up a picture of the breast tissue. It can show whether an abnormal area is solid (made of cells) or is a fluid-filled cyst.

You'll be asked to take off your top and bra, and lie down on a couch with your arm above your head. The person doing the scan puts a gel onto your breast and moves a small, handheld device around it. A picture of the inside of the breast shows up on a screen. They may also do an ultrasound of the lymph nodes in your armpit. An ultrasound only takes a few minutes and is painless.

## **Breast biopsy**

A biopsy is needed to diagnose DCIS. The doctor injects a local anaesthetic and then takes a small piece of tissue or cells (biopsy) from any abnormal areas. A doctor called a pathologist, who is a specialist in analysing cells, examines the tissue or cells under a microscope to look for cancer cells.

For a few days afterwards, your breast may feel sore and bruised. Taking painkillers will help with this. Any bruising will go away in a couple of weeks.

There are different ways of taking a biopsy. Your doctor or nurse will explain the type of biopsy you will have. As DCIS can't usually be felt, you will need a mammogram or ultrasound to guide the biopsy needle to the abnormal area.

## **Core needle biopsy with mammogram**

A mammogram may be used to guide the biopsy. This is known as a stereotactic core needle biopsy.

You'll be positioned in a mammography machine (see page 15) that has a special device attached. In most units, the test is done while you're sitting down. In a few units, women are asked to lie on their front. The radiographer then takes an x-ray of your breast from two different angles to work out the exact position of the abnormal area. A needle can then be inserted into the right place to take a sample.

## Ultrasound-guided needle biopsy

Sometimes an ultrasound scan is used to show where the abnormal area is. This helps the doctor guide a needle through the skin into the exact area to be sampled. You'll have a few biopsies taken from the area. You may feel some pressure, but this should only last for a short time.

## Vacuum-assisted biopsy (VAB)

A mammogram or ultrasound helps the doctor to guide this biopsy needle to the correct area of the breast. The doctor uses a vacuum method to gently withdraw pieces of tissue into a small collecting chamber. Several biopsies can be taken without needing to remove the needle and put it in again.

## Clip insertion

When a core biopsy is performed, a tiny metal clip is often placed in the area. This helps the surgeon to find the area again if you need an operation. The clip is very small and won't cause any problems, even if it is not removed.

'Waiting for the test results was probably the most difficult time because I felt there was something wrong but I didn't know. And I didn't know how bad it was. Your mind goes like wildfire because you're thinking of all the possible scenarios.'

**Pauline**



## Other tests

If it isn't possible to remove enough tissue to make a diagnosis with a needle biopsy or a VAB, you may need a small operation. You'll be referred to a specialist breast surgeon to have an excision biopsy under a general anaesthetic.

### Excision biopsy

The surgeon makes a cut in the skin of the breast and takes a biopsy of the breast tissue. You usually go home on the day of your operation but some people may need to stay in hospital overnight. Usually, you have stitches that dissolve and don't need to be removed.

### Wire localisation

Sometimes an x-ray or ultrasound is used to guide a fine wire into the breast. This is to mark exactly where the surgeon should take the biopsy. The surgeon removes the wire when the excision biopsy is done.

Sometimes the surgeon injects a tiny amount of a harmless radioactive substance into the area of micro-calcification. The surgeon then uses a special hand-held probe during surgery to guide them to the area that needs to be biopsied.

### Examining the tissue under a microscope (pathology)

A doctor who specialises in cell types (a pathologist) will use a microscope to examine the tissue taken during a biopsy. The pathologist looks at the type of cells and how abnormal they are (see pages 26–27). All this information is reported back to your breast specialist.



## Biopsy and test results

Waiting for test results can be a difficult time. You may find it helpful to talk with your partner, family or a close friend. The organisations listed on pages 95–99 can also provide support. You can talk things over with one of our cancer support specialists on **0808 808 00 00**.

If your biopsy results confirm that you have DCIS, you'll be referred to a breast unit for treatment. You may also be referred to the unit if the test results are unclear. You'll be seen by a specialist breast surgeon and a breast care nurse for information and support.

'I went back in and I had further tests and a biopsy. Things moved quickly. I was given the diagnosis in December and then I was heading for surgery in January. The consultant was great when it came to telling me what we were dealing with, but it was very surreal. He explained everything and gave details and diagrams, but it is very hard to process.'

Wendy

# Staging and grading

Your breast specialist needs certain information about the DCIS to help plan the best treatment for you. This includes information about the stage and grade of the cancer and whether it has certain hormone receptors.

## Staging

The stage of a cancer describes its size and whether it has spread from where it started. DCIS is described as stage 0. This is the earliest stage and means there is no invasive breast cancer. DCIS can be any size but will always be stage 0.

## Grading

The grade of a cancer describes how the cells look and how quickly they grow compared with normal cells. In DCIS, the grade of the cells is important. It shows how likely DCIS is to come back in the breast, or to develop into an invasive cancer. There are three grades:

- **Low-grade DCIS** – The cells look similar to normal breast cells and usually grow slowly. The cancer cells are less likely to spread into surrounding tissue.
- **Moderate- or intermediate-grade DCIS** – The cells look more abnormal and grow slightly faster than low-grade DCIS.
- **High-grade DCIS** – The cells look quite different from normal breast cells and grow more quickly.

High-grade DCIS is more likely to come back or develop into an invasive cancer than low-grade DCIS. Low-grade DCIS can still develop into invasive cancer, but this would usually take many more years than for a high-grade DCIS.

Knowing the grade of the DCIS helps 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 lobules or ducts. These very small areas of spread are called areas of microinvasion.

## Hormone receptors

DCIS cells may have receptors on them that allow hormones, such as oestrogen, to attach to the cancer cell. These hormones can help the cancer cells to grow. The tissue that is removed at surgery is tested for oestrogen receptors.

If DCIS is oestrogen-receptor positive (ER-positive), your doctor may talk to you about hormonal therapy treatment (see pages 58–60). However, hormonal therapy isn't standard treatment for DCIS.



**'They told me that the lump in my breast would need to be removed straight away. Then further tests would determine if I needed more treatment.'**

**Wendy**

# TREATING DCIS

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# Treatment overview

This section gives a brief overview of treatment for DCIS. The aim of treatment is to remove the DCIS and reduce the risk of it coming back or developing into an invasive breast cancer. Each treatment is explained in more detail in the next few chapters.

Surgery to remove the DCIS is the main treatment. This may be the only treatment you need. Women are usually treated with an operation that keeps as much of the breast and its shape as possible. This is called a wide local excision (WLE). In certain situations, a woman may be advised to have the whole breast removed (mastectomy). If you have a mastectomy, you'll usually also have a sentinel lymph node biopsy. This is a way of checking the lymph nodes in the armpit for cancer cells.

You'll be given the option to have breast reconstruction done at the same time as a mastectomy.

There is more information about surgery on pages 36–51.

Usually, doctors recommend radiotherapy (see pages 52–57) after WLE to reduce the risk of DCIS coming back or of an invasive breast cancer developing.

If you have ER-positive DCIS (see page 27), you may have hormonal therapy (see pages 58–60), although this isn't routinely used for DCIS.

Not all DCIS will develop into invasive cancer. For some women with low-grade DCIS, there may be an option of having no treatment or having hormonal therapy and then keeping the DCIS under close supervision.



Research trials are being carried out to see whether less treatment is possible. We discuss research trials on pages 61–63. Your doctor or specialist nurse can give you more information about possible research trials.

It can be difficult to make decisions about treatment. It's important to think about the benefits and disadvantages, and to take your time when deciding. The information here and in the next few chapters may help you to decide.

## Multidisciplinary team (MDT)

A team of specialists will meet to discuss and decide on the best treatment for you. After the MDT meeting, your doctor will talk to you about your treatment choices. This multidisciplinary team (MDT) will include:

- a specialist breast surgeon
- a breast reconstruction surgeon
- a specialist breast care nurse who gives information and support
- clinical oncologists – doctors who specialise in treating cancer using radiotherapy and drug treatments (such as hormonal therapy)
- a radiologist who reads mammograms and analyses scans
- a pathologist who examines cells under the microscope and advises on the type and extent of the cancer.

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

## Making treatment decisions

Some people find it very hard to make decisions about treatment. If you're asked to choose between treatments or whether to have treatment, make sure that you have enough information. Your specialist can explain what's involved and any possible side effects of the treatment so you can decide what's right for you.

Some women with DCIS are concerned about having treatment for a condition that isn't life-threatening. However, most women accept that it's important to treat DCIS to prevent it from developing into an invasive cancer. The aim of treatment is to reduce the risk of developing invasive breast cancer.

Because there are different options, it's important to think about what's right for you. DCIS doesn't need to be treated urgently, so you can take time to think things over. You should ask questions or discuss anything you don't understand with your surgeon or breast care nurse.



You may find our booklet **Making treatment decisions** useful.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

'At first I was completely of the mind that I wanted a mastectomy. If there was any risk, I thought they might as well just take the whole breast. But I took the advice of the surgeon who told me that it was not necessary.'

**Wendy**

## Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

If you decide not to have treatment, a senior doctor will talk to you to make sure you are aware of all the options available. You will also be advised that you will be seen at any time if you change your mind.



# Surgery

Surgery is the main treatment for DCIS. The operation you have depends on the size and position of the DCIS and your own preference. Your surgeon and breast care nurse will talk to you about your options.

Your surgeon will usually recommend surgery that keeps as much of the breast and its shape as possible. This surgery is called a wide local excision (WLE).

In some situations, the surgeon may recommend having the whole breast removed (mastectomy). The surgeon may take a sentinel lymph node biopsy (SLNB) during the mastectomy operation. This is to make sure that there is no small invasive cancer present which has spread to the lymph nodes.

You can usually choose to have breast reconstruction (making a new breast shape) at the same time as the mastectomy or later. Some women may decide not to have breast reconstruction at all.

## Wide local excision (WLE)

The surgeon removes the DCIS and some of the normal-looking tissue around it (a clear margin). This is called a wide local excision. You will usually have a fine wire inserted to mark the area so the surgeon can find it more easily. This is called wire localisation (see page 24).

After WLE, most women are advised to have radiotherapy to reduce the risk of DCIS returning or of an invasive cancer developing (see page 9). If the area of DCIS was very small and low or intermediate-grade, WLE may be the only treatment you need.

## Clear margins

After surgery, the pathologist examines the tissue in the edges of the tissue (margin) around the DCIS. If there are any cancer cells at or close to the margin (a positive margin), you will need another operation to remove more tissue. Making sure the margins are clear reduces the risk of the cancer coming back in the breast. If your surgeon thinks a second operation is unlikely to clear all the DCIS cells, you may be advised to have a mastectomy.

## Mastectomy (removing the breast)

Breast surgeons will usually try to conserve a woman's breast whenever possible. But sometimes they may recommend a mastectomy. This may be when the DCIS:

- covers a wide area
- is in more than one part of the breast and the affected areas are not small.

Before the operation your surgeon will talk to you about sentinel lymph node biopsies (see pages 41–42) and options for breast reconstruction (see pages 42–43).

## Making decisions about surgery

It can be difficult to make treatment decisions. You may be offered the choice of a wide local excision or a mastectomy. Surgery to your breast can affect your feelings of femininity, your sex life and relationships. When deciding about surgery, it's important to take your time and to have all the information you need to make the right decision for you.

Both wide local excision and mastectomy have the same long-term results in terms of treating DCIS. It's helpful to think about the possible advantages and disadvantages of each before making a decision.

### Wide local excision

#### Advantages

- It keeps the appearance and sensation of the breast.
- Recovery is shorter and easier than with a mastectomy.
- It may be less likely to affect your sex life and relationships.

#### Disadvantages

- You may need more than one operation to get clear margins.
- You will usually need radiotherapy after the surgery
- Radiotherapy has short-term side effects, and some women may have long-term side effects.
- You may still worry about the cancer coming back somewhere else in the breast.



## Mastectomy

### + Advantages

- You may not need radiotherapy.
- You may feel less anxious as all the breast tissue has been removed.

### - Disadvantages

- You lose your breast permanently.
- It takes longer to recover after having a mastectomy.
- It changes your appearance which may affect your confidence, sex life and relationships.
- You will need a longer operation and possibly further surgery if you want breast reconstruction afterwards. However, reconstruction may help to reduce disadvantages for some women.

Your doctors and breast care nurse can answer any questions you may have and tell you what to expect. They may have photographs of other women who've had surgery, which they can show you.

Talking to other women who've already had surgery can also help – you can contact them through Breast Cancer Care (see pages 95–96). Your breast care nurse may know of a local cancer support group where you can talk to someone who's had a similar operation.



## Sentinel lymph node biopsy (SLNB)

During surgery, your surgeon may remove a few lymph nodes from the armpit to see if they contain cancer cells. Women who have a mastectomy usually have an SLNB done during the operation. Women having a wide local excision do not usually have an SLNB, unless the surgeon thinks there may be an invasive cancer present.

A sentinel lymph node biopsy is a way of checking the smallest possible number of lymph nodes (usually 1–3) in the armpit. The sentinel nodes are the first ones that lymph fluid drains to from the breast, so they are the most likely nodes to contain any cancer cells. If the sentinel nodes don't contain cancer cells, you won't need surgery to remove any more lymph nodes.

Removing the smallest possible number of lymph nodes reduces the risk of side effects that can occur after lymph node surgery. These include swelling of the arm, known as lymphoedema (see pages 70–71) and stiffness of the arm (see page 47).

### How an SLNB is done

A doctor or hospital technician injects a tiny amount of radioactive liquid, which is harmless, into your breast. This is usually around the nipple. You have this done on the day of surgery or sometimes the day before.

The surgeon may also inject a blue dye into your breast, which stains the lymph nodes blue. The sentinel lymph nodes absorb the radioactivity or become blue first. The surgeon uses a small hand-held instrument to find the lymph nodes that have picked up the radioactivity. They only remove the blue or radioactive nodes (sentinel nodes), which are tested to see if they contain cancer cells.

The nodes that are removed are examined by the pathologist to make sure there are no cancer cells. If the sentinel lymph nodes contain cancer cells, it means there is an invasive cancer in the breast and not only DCIS.



We have separate information about invasive breast cancer.

## 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 (immediate breast reconstruction). Some women prefer to leave reconstruction until a later time, and others may decide not to have it done at all. It depends on what's right for you.

If you're not having immediate reconstruction but think you might want to have breast reconstruction in the future, it's a good idea to mention this before you have a mastectomy. You don't have to make a final decision at this stage, but it will help the surgeon to plan your operation.

Breast reconstruction is specialised surgery. It is done by a plastic surgeon or an oncoplastic surgeon (experts in breast cancer surgery and reconstruction). There are different methods of reconstruction. A new breast shape can be made using a silicone implant or with fat, and sometimes with muscle from your back or tummy.

Occasionally, women with bigger areas of DCIS and larger breasts can have the DCIS removed and both breasts reshaped. The treated breast will be smaller than before, so the other breast is reduced in size to leave you with a symmetrical appearance. This is called a therapeutic mammoplasty. There is a higher risk of short-term complications following this operation, but often only one operation is needed and the results are usually good.

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



Our booklet **Understanding breast reconstruction** gives more detailed information about the different types of surgery.

'I went through eight hours of surgery to remove the cancerous cells and then reconstruct my breast from my abdominal muscles – some women pay £4,000 to have a tummy tuck like mine, which is the 'silver lining'. It's a bigger operation than having implants but it gives a very natural breast shape.'

**Bronwen**

## Before your operation

At the breast clinic, your surgeon or breast care nurse will talk to you about how your breast will look after your surgery.

Before your operation, you may be seen at a pre-assessment clinic. This gives you a chance to ask questions and talk over any concerns about the operation. You may have tests to check your general health. These can include blood tests, a urine check, chest x-ray or a recording of your heart (ECG).

You will usually come into hospital on the day of your operation. You'll meet the doctor who will give you an anaesthetic (the anaesthetist). The nurses will give you elastic stockings (TED stockings) to wear during and after the operation to help prevent blood clots.

If you smoke, your wound can take longer to heal, especially if you have a mastectomy with reconstruction. This is because smoking can damage the blood supply to the skin which can affect wound healing. If you're able to give up smoking, the earlier you can do it before surgery the better.



We can send you more information about giving up smoking.

## Time in hospital

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

Most women who have breast cancer surgery can go home the same day or the following day. But if you have breast reconstruction at the same time as a mastectomy, you will be in hospital for longer (1–5 days). This will depend on the type of reconstruction operation you have.

## After the operation

You'll be encouraged to get out of bed and start moving around as soon as possible after your operation.

## Your wound

You'll have a dressing covering your wound, which may be left undisturbed for the first few days. The nurses will tell you how to look after it when you go home.

How long it takes to heal depends on the operation you had. If you only had a small area of tissue removed, your wound will usually heal quickly. If you don't have stitches that dissolve, you will probably have your stitches removed about 7–10 days after your operation. For some women, particularly those who smoke, the wound can be slower to heal and may need further attention from your surgeon. Let your doctor know if you are concerned about how your wound is healing.

Wound infection can be a complication of surgery. Signs of infection can include warmth, redness, swelling around the wound or discharge from it. You may also feel unwell with a high temperature. Tell your nurse or doctor if you get any of these symptoms, even after you go home.

## **Drains**

You may have a long, thin plastic tube at the wound site that drains fluid from your wound into a bottle. If you have had a mastectomy, it is usually left in until it stops draining, which may take a few days. You can go home with the drain. A practice nurse or a district nurse may check it when you're at home. Or you might have it checked and removed at the hospital.

## **Pain**

You may have some pain around the wound. This may last a few days. The nurses will give you painkillers to take regularly until it settles down. After a mastectomy, you may need to take them for a week or two. Let your doctor or nurse know if the painkillers aren't helping or cause any side effects.

## **Fluid collecting around the wound (seroma)**

Fluid can build up in the area around the wound. This is called a seroma. It usually goes away within a few weeks. Sometimes your nurse or doctor may need to drain it off with a needle and syringe.



## Stiff shoulder or arm

After a mastectomy or sentinel lymph node biopsy, your shoulder or arm may feel sore or stiff. It's important to do the arm exercises that your physiotherapist or nurse shows you. This will help improve the movement in your shoulder and arm, and reduce the risk of long-term problems. You should start the exercises the day after your operation and gradually build up what you can do.



**Breast Cancer Care (see pages 95–96) has a leaflet about these exercises.**

## Numbness and tingling in the breast area and arm

It's not common to have problems with your arm because the lymph nodes in the armpit aren't usually removed. However, most women who have had a mastectomy will have changes in sensation in the area of the breast and in the upper arm. This is because the nerves in the area have been affected by the surgery. This numbness and tingling usually gets better within a few months, but occasionally the changes, mainly numbness, can be permanent.

## How your breast looks

It is common to have swelling and bruising after your operation. It should improve after a few weeks, but let your breast care nurse know if it doesn't. Wearing a crop top or sports bra might feel more comfortable until the swelling settles. If you had an SLNB (see pages 41–42), you may see the blue dye in the skin for a while, but this is normal.

### Scars

All breast surgery leaves some type of scar. How your breast looks afterwards will depend on the operation you have. After WLE, you'll usually have a small scar and sometimes a small dent in the breast. A mastectomy scar is across the skin of the chest and into the armpit.

To begin with, your scar will be red if you have white skin, or darker if you have dark skin. It will also be firm and slightly raised. Over time, it will flatten and fade. Everyone's skin heals differently. If you have dark skin or fair, freckled skin, scars can take longer to settle and may be more noticeable for longer.



If you are worried about your scar, talk to your breast care nurse or surgeon. There's also more information about scarring after breast reconstruction in our booklet **Understanding breast reconstruction**.

## Coping with a changed appearance

The first time you look at your breast or chest area after your operation, you may prefer to be alone or may like to have someone with you.

At first, the area will look swollen and bruised, but this will settle in the next few weeks. In time, the scar becomes less obvious. If you have had a mastectomy you may notice extra tissue at the ends of the wounds. These often settle with time, but if they don't a second simple operation can flatten them out. After a wide local excision some women notice over time that the treated breast becomes smaller and does not match the other breast.



We have a booklet called **Body image and cancer** that you might find helpful.

Changes to your appearance can affect your confidence and feelings about yourself as a woman. They can also affect your sex life (see pages 68–69). Talk to your doctor or breast care nurse if you are unhappy about your appearance. Some women find that further surgery or breast reconstruction (see pages 42–43) helps give them back their confidence and feelings of femininity.

'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.'

**Maggie**

## Breast prosthesis

If you have a mastectomy and don't have immediate breast reconstruction, your nurse will give you a soft, lightweight prosthesis (false breast) to wear inside your bra. It's often called a 'cumfie' or 'softie'. You can start wearing it straight after your operation.

When your wound has healed, you can choose a permanent prosthesis. This will closely match the size and shape of your other breast. It's made of soft plastic (silicone) and matches your skin colour. Your confidence will gradually improve as you get used to it. You can get different types of prosthesis from the NHS. Breast Cancer Care (see pages 95–96) can also give you a list of suppliers.

## When you get home

Your recovery will depend on the type of operation you had. It's important to follow the advice you've been given by your breast care nurse.

Try to get plenty of rest and eat well. Do some light exercise, such as walking, that you can gradually increase. This helps build up your energy. It's important to carry on with the exercises you were shown in hospital. You may need to avoid lifting or carrying anything heavy for a few weeks. Your nurse will give you more information, as it depends on the type of operation you had.

Some insurance policies give time limits for not driving after surgery. Most women are ready to drive a few weeks after their operation. Don't drive unless you feel in full control of the car.

There's more information about some after-effects and things you can do to help yourself after treatment on pages 68–75.

## Outpatient appointment and results

You will be given an appointment for the outpatient clinic to see the surgeon and breast care nurse. They will check that the wound is healing properly. They'll also tell you about the tissue that was removed during surgery (pathology) and the stage of the cancer.

'The surgery went very well. I had further tests and then the breast consultant basically told me that they were happy and that they had got it all and there were no signs that it had spread.'

**Wendy**

If you had a WLE, your surgeon will explain whether the margins around the DCIS were clear or whether you need another operation. Sometimes a small area of invasive cancer is found along with the DCIS. Although this can be distressing news, it's usually very early breast cancer, which can be treated successfully. If invasive cancer is found, you may have to have a second operation to do a sentinel lymph node biopsy if you have not already had one.

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



We have separate information about invasive breast cancer in our booklet **Understanding breast cancer**.

# Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is given after surgery to destroy any possible remaining cancer cells. You may be given it to reduce the risk of DCIS coming back or an invasive cancer developing. You usually start radiotherapy about four weeks after surgery.

After a wide local excision, your cancer specialist will recommend you have radiotherapy to the breast after your operation. Some women also have an extra dose to the area where the cancer was (a boost dose). Your cancer specialist may recommend radiotherapy if the DCIS is large or high-grade (see pages 26–27).

If you've been advised to have radiotherapy, your cancer specialist (clinical oncologist) will explain why it's recommended for you. It's important to talk about any concerns you may have with your specialist and your breast care nurse.



We can send you a booklet called **Understanding radiotherapy**.

## How it is given

You usually have radiotherapy for between three and five weeks. It's given to you as an outpatient, so you come in for treatment and can then go home again afterwards. You have the treatment in the hospital radiotherapy department as a series of short daily sessions.

Each treatment session takes 10–15 minutes and they are usually given Monday–Friday, with a rest at the weekend. Your cancer specialist or nurse will talk to you about the treatment and possible side effects.



Radiotherapy doesn't make you radioactive, and it's safe for you to be with other people, including children, after treatment.

## Planning radiotherapy

Radiotherapy has to be carefully planned to make sure it is as effective as possible. The planning is to make sure the radiotherapy rays are aimed exactly at the treatment area, causing the least damage to the surrounding healthy tissue.

Treatment is planned by a cancer specialist (oncologist) and the planning may take a few visits. On your first visit to the radiotherapy department, you'll have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You usually have markings made on your skin to show the exact place where the radiographers (who give you your treatment) direct the rays. Usually, permanent markings (tattoos) the size of a pinpoint are made. They're only done with your permission. It can feel a little uncomfortable while they're being made, but it makes sure treatment is given to the right area.

Radiotherapy is normally given to the whole breast. You may also be given an extra (boost) dose to the exact area where the DCIS was.



Radiotherapy planning



## Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you'll be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

## Positioning

You'll need to be able to position your arm so that the radiotherapy machine can give the treatment effectively. A physiotherapist can show you exercises to do to make this easier if your muscles and shoulder feel stiff or painful.



We have a video of an oncologist explaining how radiotherapy is given and showing the machine. Visit [macmillan.org.uk/radiotherapy](https://www.macmillan.org.uk/radiotherapy)

## Side effects of radiotherapy

You may develop side effects over the course of your treatment. These usually disappear gradually over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you so you know what to expect. Let them know about any side effects you have during or after treatment, as there are often things that can be done to help.

## Skin changes

Your skin in the treated area may get red, dry and itchy. Dark skin may get darker or have a blue or black tinge. 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. Skin reactions settle down 2–4 weeks after radiotherapy.

Here are some tips to help with skin irritation:

- Don't put anything on your skin in the treated area without checking with your nurse or radiographer first.
- Have a tepid or warm shower rather than a bath if you can. Turn away from the spray to protect your breast.
- Pat the area dry gently with a soft towel. Don't rub the skin.
- Wear loose clothing or crop tops, as they are less likely to irritate your skin.

You need to avoid exposing the treated area to sunshine for at least a year after treatment finishes. Use suncream with a high sun protection factor (SPF) of at least 30 to protect your skin.

## Tiredness (fatigue)

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels.

## Aches and swelling

You may have a dull ache or shooting pains in the breast that last for a few seconds or minutes. You may find that your breast becomes swollen during treatment. These effects usually improve quickly after treatment. Some women still have occasional aches and pains in the breast area after radiotherapy.

## Long-term side effects

Radiotherapy to the breast can sometimes lead to long-term side effects, but most of these are rare.

If you continue to have pain or discomfort after treatment, talk to your doctor or breast care nurse.

The most common effect is a change in how the breast looks and feels. Small blood vessels in the skin can be damaged, which can cause red 'spidery' marks on the skin (telangiectasia). Your breast may feel firmer and shrink slightly in size. Some women choose to have surgery to improve the appearance of their breasts. You may be offered surgery to reduce the size of the untreated breast or to make the treated breast larger.

It's rare for radiotherapy to the left breast to cause any heart problems. Lung or ribs problems because of radiotherapy are also rare.



Our booklets **Coping with fatigue** and **Managing the late effects of breast cancer treatment** have more information. Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) to order these free resources.

# Hormonal therapies

Hormones occur naturally in the body and help control how cells grow and what they do. Hormones, particularly oestrogen, can encourage breast cancer cells to grow.

Hormonal therapies reduce the level of oestrogen in the body, or prevent it from attaching to the cancer cells. They are only given to women who have oestrogen-receptor positive cancers – see page 27 for more information about this type of cancer.

Hormonal therapies are commonly prescribed for women with invasive breast cancer because they reduce the risk of breast cancer coming back. Doctors know that there are benefits of using hormonal therapy for DCIS, but they don't know exactly how useful this treatment is. Hormonal therapies are mainly given to treat DCIS in research trials (see pages 61–63). The type of hormonal therapy you have depends on whether you've been through the menopause or not.

## Tamoxifen

Trials have shown that a hormonal therapy called tamoxifen may reduce the risk of ER-positive DCIS coming back. It can also reduce the risk of invasive cancer in both breasts. However, the amount of benefit isn't clear so tamoxifen isn't used routinely in all women.

Your specialist will explain the possible advantages of tamoxifen in your situation. It can be used whether you have been through the menopause or not.

Tamoxifen is taken daily as a tablet, usually for five years. The side effects are similar to the effects of the menopause and may include:

- hot flushes and sweats
- vaginal dryness or an increased vaginal discharge
- weight gain
- tiredness
- leg cramps.

For women who've been through the menopause, tamoxifen can slightly increase the risk of womb (endometrial) cancer, blood clots in the leg and strokes. Although this sounds frightening, these effects are very rare. If they occur, they're usually picked up very early when they can be successfully treated



We can send you more information about tamoxifen and its effects. We also have more information about breast cancer and menopausal symptoms, which may be helpful.

## Aromatase inhibitors

Aromatase inhibitors (AIs) are the main hormonal therapy used in women with invasive breast cancer after the menopause. Like tamoxifen, these drugs only work in ER-positive DCIS. They stop oestrogen being made in the fatty tissue.

Research has shown that they can be used to treat DCIS, but they aren't a standard treatment. There are trials to find out which women should have them. Your doctor or breast care nurse can tell you more about any trials that you may be suitable for.

Your doctor may prescribe an aromatase inhibitor such as:

- anastrozole (Arimidex®)
- exemestane (Aromasin®)
- letrozole (Femara®).

These drugs are taken daily as a tablet. Side effects can include tiredness, joint and muscle pain, vaginal dryness or hot flushes.



# Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

## Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.





If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

## Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.



Our website has links to clinical trials databases, which have details of current research trials on breast cancer. Visit [macmillan.org.uk/clinicaltrials](https://www.macmillan.org.uk/clinicaltrials). We have more information about clinical trials in our free booklet **Understanding cancer research trials (clinical trials)**.



# AFTER TREATMENT FOR DCIS

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## Follow-up

After treatment finishes, you'll have regular check-ups. If you are below screening age, you will have yearly mammograms until you enter an NHS Breast Screening Programme. If you are already having screening, you will have a mammogram every year for 5–10 years and then go back to three-yearly screening. If you are over the screening age, you can choose to have regular screening. You won't receive an invitation letter, but you can contact your local screening clinic to arrange it.

After your surgery or radiotherapy, your follow-up appointments may be every few months at first, but eventually are likely to be once a year. Appointments are a good opportunity for you to talk to your doctor or nurse about any concerns you have. But if you notice any new symptoms between appointments, you can contact your doctor or nurse for advice.

Instead of routine appointments, some women are given information on what to look out for by their breast care nurse. They are asked to contact their nurse or cancer specialist if there's anything they're worried about. Some women may have their follow-up appointments at a nurse-led clinic and only see their cancer specialist if something needs to be checked further.

Many women find they get anxious for a while before the appointments. This is natural. It can help to get support from family, friends or one of the organisations listed on pages 95–99. You can also contact the Macmillan Support Line on **0808 808 00 00**.

## Breast awareness

Although you'll have yearly mammograms for 5–10 years, it's still a good idea to be aware of what's now normal for you. Your treated breast will look and feel different depending on the treatment you've had.

Your breast care nurse can tell you what you should expect and what to look out for. It's also important to be aware of what to look out for in your untreated breast.

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

## If DCIS comes back

After treatment, the risk of DCIS coming back or of an invasive cancer developing is low. If any new problems develop, they will usually be picked up very early.

If DCIS comes back or an invasive cancer develops in the same breast, you'll usually be advised to have a mastectomy. If you haven't had radiotherapy, it might be possible to remove the area with surgery and then have radiotherapy. Treatment for DCIS that comes back or for early invasive breast cancer that develops after treatment for DCIS is usually very successful.

## After treatment

You'll probably be keen to get back to the things you did before being diagnosed. But you may still be coping with some side effects of treatment and with some difficult emotions.

It's important to talk about any concerns or questions you have with your cancer specialist and breast care nurse. After treatment, you may want to know what to expect, whether there's anything you should avoid, how to make the most of your health and where to get support.

You may find it helpful to read our leaflet **What to do after treatment ends: 10 top tips**.

### Effects on your sex life

DCIS, its treatments and side effects may affect your feelings about yourself as a woman and your sex life. Difficulties often gradually improve after treatment, although for some women, it may take longer.

You may feel insecure and worry whether or not your present or a future partner will find you sexually attractive. It can help to try to talk about it with them if you feel things are awkward between you.

Cuddles, kisses and massages can show how much you care for someone, even if you don't feel like having sex. You can wait until you and your partner feel ready – there's no right or wrong time.

Our booklet **Sexuality and cancer** has more information and tips that may help you.

Let your doctor or nurse know if any difficulties with your sex life don't improve. They may be able to reassure you and can 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 – visit **cosrt.org.uk**

## Contraception

Your doctor will advise you not to use contraception that contains hormones as these can slightly increase the risk of breast cancer. This includes the pill or coils (intra-uterine devices) that release hormones. Your specialist or breast care nurse can give you advice about other forms of contraception. Coils that don't contain hormones or barrier methods, such as condoms or the cap, are usually the most suitable.

## Hormone replacement therapy (HRT)

Doctors don't recommend hormone replacement therapy (HRT) because it contains oestrogen, which could encourage breast cancer cells to grow.

There are other ways that menopausal symptoms can be treated. If hot flushes are troublesome, your doctor can prescribe medication to help. There are also different lubricants and creams that help improve vaginal dryness. Your breast care nurse can give you advice on managing menopausal symptoms.

Some doctors may occasionally prescribe HRT for severe menopausal symptoms when nothing else has helped. Women need to talk about this with their doctor so they are aware of the possible benefits and risks.

We can send you some information about breast cancer and menopausal symptoms, which has tips on managing these effects.

## Lymphoedema

Lymphoedema is a swelling of the arm that sometimes happens after surgery or radiotherapy to the lymph nodes in the armpit. It can develop months or years after treatment. If you had a sentinel lymph node biopsy (see pages 41–42), your risk of lymphoedema is small.

There are things you can do to help reduce your chances of developing lymphoedema. It's important to protect your arm and hand, and to look after the skin in that area.

Here are some tips:

- Keep your skin clean and moisturise it every day with unperfumed cream or oil to keep it in good condition.
- Wash small grazes and cuts straight away, put on antiseptic cream and cover if necessary.
- See your GP straight away if you get signs of infection around a cut, for example, if it becomes red, hot or swollen.
- Wear gloves and long sleeves when doing household tasks, DIY, gardening or when handling animals/pets.
- Use nail clippers to cut your nails and don't push back or cut the cuticles – use cuticle cream instead.



- Use an electric razor if you shave under your arms.
- Cover up in the sun and use a suncream with a high sun protection factor (SPF) of at least 30.

If you notice any swelling in your arm, hand or chest, always get it checked by your doctor or nurse.



Our booklet **Understanding lymphoedema** has more information about lymphoedema. There's also a video on our website explaining it – visit [macmillan.org.uk/whatislymphoedema](https://www.maccmillan.org.uk/whatislymphoedema)





# Making healthy choices

After treatment, some women choose to make some positive lifestyle changes. Even if you followed a healthy lifestyle before, you might want to focus more on making the most of your health. This can be done by making small, achievable changes to the way you live that will improve your health and well-being.

## Keep to a healthy weight

There's some evidence that keeping to a healthy weight after the menopause may help reduce the risk of breast cancer coming back. Your GP can advise you and give you information on your ideal weight. We already know it reduces the risk of heart problems, diabetes and developing some other cancers. 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
- become more physically active.



There is more information about healthy eating in our booklets **Healthy eating and cancer**, and **Managing your weight after cancer treatment**.

## Stick to sensible drinking

Stick to sensible drinking guidelines, which recommend that women drink less than two units a day or 14 units a week. Try to have a few alcohol-free days a week.

## Stop smoking

If you're a smoker, giving up smoking is the healthiest decision you can make. It's a major risk factor for smoking-related cancers and heart disease.



## Get physically active

Being physically active helps to keep your weight healthy and can reduce stress and tiredness. It helps to keep your bones strong and your heart healthy. This can be an important part of your recovery after treatment. It can help you to feel better in yourself and help to build up your energy levels. It also reduces the risk of heart disease, stroke and diabetes. Talk to your cancer specialist or GP before you start exercising. Start slowly and increase your activity over time.



We have a booklet called **Physical activity and cancer treatment**, which has more information.

## Reduce stress in your life

Being diagnosed with DCIS can be a stressful time in your life. One way of coping with stress is to make time to relax. Relaxing can be as simple as having a meal with friends or family, going for a walk, enjoying a bath, listening to music or watching a film. These can all help you to reduce any anxiety.

## Share your experience

When treatment finishes, you might find it helps to talk about it with other people and share your thoughts, feelings and advice. Just hearing about how you've coped, what side effects you had and how you managed them is very helpful to someone who is about to start treatment.

We can help you share your story to help others. Visit **macmillan.org.uk/cancervoices** for more information or call us on **0808 808 00 00**





# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

Although DCIS isn't 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.

We have a booklet called **How are you feeling? The emotional effects of cancer**, which discusses some of the feelings you may have, things that can help and where to get support.

The type of treatment you've had will have an effect on how you feel. For some women, treatment is straightforward, but for others it may mean changes in appearance or having to cope with side effects.

Talking to family and friends about your feelings often helps. You can get advice and support from your doctor or specialist nurse too, or ask to be referred to a trained counsellor.

Our cancer support specialists on freephone **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

'I've had lots of emotions after having had my breast removed. I've discovered that it is like a bereavement. It's a big deal. But you can get through it.'

**Gillian**



## Support groups

Self-help or support groups offer a chance to talk to other women who understand what you are going through. You can call us or visit our website for information about support groups in your area.

## Online support

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



Our online community [macmillan.org.uk/community](https://www.macmillan.org.uk/community) is a social networking site where you can chat to people in our chat rooms, blog your journey, make friendships and join support groups.

'I want to do whatever I can to give myself the best shot of making it into proper old age. I realise that life is for living. I treat myself more. I go on lots of cruises and am planning a big holiday. I like to do things like that now, which I might not have done before.'

Wendy



# 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, and their fears can sometimes 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 of your illness.



Our booklet **Talking to children when an adult has cancer** includes discussion about sensitive topics. There's also a video on our website that may help, at [macmillan.org.uk/talkingtochildren](https://www.macmillan.org.uk/talkingtochildren)



# WORK AND FINANCIAL SUPPORT

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# Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.



We have booklets about work and cancer and working while caring for someone with cancer. There's also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

# Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- **contributory** – you can get this if you have made enough national insurance contributions
- **income-related** – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

**Personal Independence Payment (PIP)** is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance in England, Scotland and Wales.

**Attendance Allowance (AA)** is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for **Carer's Credit**. This helps you to build up qualifying years for a State Pension.

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.



You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 99) or Citizens Advice (visit **citizensadvice.org.uk**). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.



Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 99.



Our booklets **Insurance** and **Getting travel insurance** may also be helpful.



# FURTHER INFORMATION

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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 leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation). There you'll also find videos featuring real-life 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
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

If you'd like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

## 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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence. Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## 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's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, 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 [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

## 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](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### Financial advice

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

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're 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](https://www.macmillan.org.uk/work)



### Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.



# Other useful organisations

There are lots of other organisations that can give you information or support.

## Useful breast cancer organisations

### Breakthrough Breast Cancer

Weston House,  
246 High Holborn,  
London WC1V 7EX  
**Tel** 08080 100 200  
**Email** supporterservices@  
breakthrough.org.uk  
**www.breakthrough.org.uk**  
Committed to fighting  
breast cancer through  
research and awareness.

### Breakthrough Breast Cancer Scotland

38 Thistle Street,  
Edinburgh EH2 1EN  
**Tel** 08080 100 200  
**Email** scotlandinfo@  
breakthrough.org.uk

### Breast Cancer Care

5–13 Great Suffolk Street,  
London SE1 0NS  
**Tel** 0808 800 6000 (9am–  
5pm, Mon–Fri, 9am–2pm, Sat)  
**Textphone** 0808 800 6001  
**Email**  
info@breastcancercare.org.uk  
**www.**

### breastcancercare.org.uk

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

### **Breast Cancer Care Scotland**

169 Elderslie Street,  
Glasgow G3 7JR

**Tel** 0845 077 1892

#### **Email**

sco@breastcancercare.org.uk

### **Breast Cancer Care Wales**

1<sup>st</sup> Floor, 14 Cathedral Road,  
Cardiff CF11 9IJ

**Tel** 0845 077 1894

#### **Email**

cym@breastcancercare.org.uk

### **Breast Cancer Haven**

Effie Road, London SW6 1TB

**Tel (The London Haven)**

020 7384 0000

**Tel (The Hereford Haven)**

01432 361 061

**Tel (The Yorkshire Haven)**

0113 284 7800

**Email** info@thehaven.org.uk

**www.breastcancerhaven.org.uk**

Provides free therapies that help people with the physical and emotional side effects of breast cancer. Specialist nurses and experts in nutrition, exercise and emotional support provide tailor-made programmes.

Has an outreach programme for people who get to the Havens.

### **The Daisy Network (premature menopause support group)**

PO Box 183,  
Rossendale BB4 6WZ

#### **Email**

daisy@daisynetwork.org.uk

**www.daisynetwork.org.uk**

A support group for women who have early ovarian failure. The website gives information about premature menopause and related issues. Also has a mailing list for subscribers and details of other helpful groups.

### **General cancer support organisations**

#### **Cancer Black Care**

79 Acton Lane,  
London NW10 8UT

**Tel** 020 8961 4151

#### **Email**

info@cancerblackcare.org.uk

**www.cancerblackcare.org.uk**

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

### **Cancer Focus Northern Ireland**

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Tel** 0800 783 3339

(Mon–Fri, 9am–1pm)

**Email** [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

### **Cancer Research UK**

Angel Building,  
407 St John Street,  
London EC1V 4AD

**Tel** 0300 123 1022

**[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)**

Has patient information on all types of cancer and has a clinical trials database.

### **Cancer Support Scotland**

The Calman Centre,  
75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email** [info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

[www.cancersupportscotland.org](http://www.cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

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

### **Macmillan Cancer Voices**

**[www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices)**

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

### **Maggie's Centres**

2<sup>nd</sup> Floor Palace Wharf,  
Rainville Road,  
London W6 9HN

**Tel** 0300 123 1801

**Email** enquiries@  
maggiescentres.org

**www.maggiescentres.org**

Provides information about cancer, benefits advice, and emotional or psychological support.

### **Penny Brohn Cancer Care**

Chapel Pill Lane,  
Pill, Bristol BS20 0HH

**Tel** 01275 371 100

(Mon–Fri, 9.30am–5pm)

**Email**

helpline@pennybrohn.org

**www.pennybrohn  
cancercare.org**

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

### **General health information**

#### **Health and Social Care in Northern Ireland**

**www.hscni.net**

Provides information about health and social care services in Northern Ireland.

#### **NHS Choices**

**www.nhs.uk**

The UK's biggest health information website. Has service information for England.

#### **NHS Direct Wales**

**www.nhsdirect.wales.nhs.uk**

NHS health information site for Wales.

#### **NHS Inform**

**www.nhsinform.co.uk**

NHS health information site for Scotland.

**Patient UK****[www.patient.co.uk](http://www.patient.co.uk)**

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

**Counselling and emotional support****British Association for Counselling and Psychotherapy (BACP)**

BACP House,  
15 St John's Business Park,  
Lutterworth,  
Leicestershire LE17 4HB  
**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

**Financial or legal advice and information****Benefit Enquiry Line Northern Ireland****Tel** 0800 220 674

(Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm)

**Textphone** 0800 243 787**[www.nidirect.gov.uk/money-tax-and-bfits](http://www.nidirect.gov.uk/money-tax-and-bfits)**

Provides information and advice about disability benefits and carers' benefits.

**Department for Work and Pensions (DWP) Disability Living Allowance****Helpline** 0345 712 3456**Textphone** 0345 722 4433**Personal Independence Payment Helpline**

0345 850 3322

**Textphone** 0345 601 6677**Carer's Allowance Unit**

0345 608 4321

**Textphone** 0345 604 5312**[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.



## 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 photographs 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 our Senior Medical Editor, Professor Mike Dixon, Professor of Surgery and Consultant Surgeon, Edinburgh.

With thanks to: Morven Angus, Clinical Nurse Specialist; Ms Nichola Roche, Consultant Breast Surgeon; Ms Karyn Shenton, Consultant Breast Surgeon and Dr Virginia Wolstenholme, Consultant Clinical Oncologist.

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

## Sources

We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at [bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)

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# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



## **Share your cancer experience**

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

## **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**

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**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

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Valid from

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Expiry date

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Issue no

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Security number

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Signature

Date / /

## Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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 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.



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to:  
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,  
89 Albert Embankment, London SE1 7UQ

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.

Braille and large print versions on request.

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**WE ARE  
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