



**NATIONAL BREAST  
CANCER CENTRE**  
INCORPORATING THE  
OVARIAN CANCER PROGRAM

# Ductal carcinoma in situ

**Understanding your diagnosis and treatment**



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Understanding your  
diagnosis and treatment

This guide was prepared with input from the National Breast Cancer Centre's Ductal Carcinoma In Situ (DCIS) Consumer Information Working Group, and produced by the National Breast Cancer Centre:

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#### **Note to Reader:**

**While every effort has been made to ensure the information in this guide is as up-to-date as possible, the detection, diagnosis and treatment of DCIS are complex and constantly changing. Readers are advised to seek expert advice when faced with specific problems. This book is intended as a guide only and should not be used as a substitute for professional advice.**

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Copies of this book can be ordered from:

The Cancer Helpline: 13 11 20

National Breast Cancer Centre: 1800 624 973

This book can also be downloaded from the National Breast Cancer Centre website:  
[www.breasthealth.com.au](http://www.breasthealth.com.au)

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- the many consumers who took the time to review and comment on drafts of this booklet
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## Note to reader

Every woman's situation and needs are different.

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Not all the information in this book will be relevant to you and your current situation.

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You don't need to read this book from cover to cover. Different chapters will be useful for you at different stages of your diagnosis and treatment.

**“I feel this experience has brought out an inner strength in me that I never knew I had.”**

**If you are reading this book for a relative or friend who does not understand English very well, you can get a professional interpreter to help. For more information, call the Translating and Interpreting Service on 13 14 50.**

## **Introduction**

The introduction of mammographic screening programs for breast cancer has seen an increase in the diagnosis of ductal carcinoma in situ (DCIS). The benefit of finding DCIS is that steps can be taken to prevent it developing into invasive breast cancer. The down side is that many women will receive significant treatments for a condition that may or may not develop into invasive disease.

Many women feel confused about the difference between a diagnosis of DCIS and invasive breast cancer. If you have been diagnosed with or are being investigated for DCIS, this booklet aims to assist you in understanding your diagnosis and making decisions about your treatment and care. Your partners, family and friends might also find it useful.

The information is based on the evidence available at the time of publication. New treatments are continually being developed and might be introduced in the future. If you hear about any technologies and treatments that are not mentioned here, please ask your doctors for more information.

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If you were found to have invasive breast cancer at the same time as DCIS, this book does not apply to you. To get a book about invasive breast cancer, contact the National Breast Cancer Centre on freecall 1800 624 973 or ask your doctor.

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# Understanding ductal carcinoma in situ

This chapter explains:

- what ductal carcinoma in situ (DCIS) is
- how DCIS differs from invasive breast cancer
- why it's important to treat DCIS
- how successful different treatments for DCIS are.

## What is DCIS?

To understand what DCIS is, it helps to know what your breast looks like on the inside. The breast contains lobules (milk sacs) that produce milk, and ducts that take the milk to the nipple. These are surrounded by fatty tissue. Sometimes the cells on the inside of the milk ducts become abnormal in shape and size, and begin to multiply in an uncontrolled way. *See illustration below.*

DCIS is the name for abnormal cells that are contained in the milk ducts of the breast. The causes of DCIS are unknown.

## A breast showing DCIS and invasive breast cancer

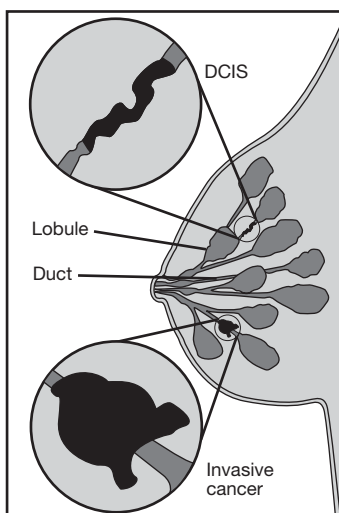


Illustration adapted from [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) with permission

# 1

## UNDERSTANDING DUCTAL CARCINOMA IN SITU

DCIS is sometimes called 'non-invasive breast cancer', a 'pre-cancer' or an 'intraductal cancer'.

## What's the difference between DCIS and invasive breast cancer?

In DCIS, the abnormal cells stay inside the milk ducts and do not spread to other parts of the breast or body. A woman cannot die from having only DCIS.

In invasive breast cancer, the abnormal cells spread outside the ducts into the breast tissue and have the potential to spread to other parts of the body. Although invasive breast cancer can be treated successfully, some women die from the disease when it spreads outside the breast.

## Why is DCIS treated?

It's thought that invasive breast cancer might start as DCIS. If you have DCIS, your risk of developing invasive breast cancer is higher than it would be if you didn't have DCIS. It's not possible to say exactly how much higher the risk is. However, some studies suggest that the risk of developing invasive breast cancer is four to twelve times higher in women treated for DCIS than for women without DCIS. Not every woman with DCIS will develop invasive breast cancer. It's not possible to tell which women will develop invasive disease.

**Treating DCIS is important to lower your risk of developing invasive breast cancer.**

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The information about risk in this chapter is based on women of different ages and with different types of DCIS. Your doctor can give you an estimate of your risk based on your individual situation.

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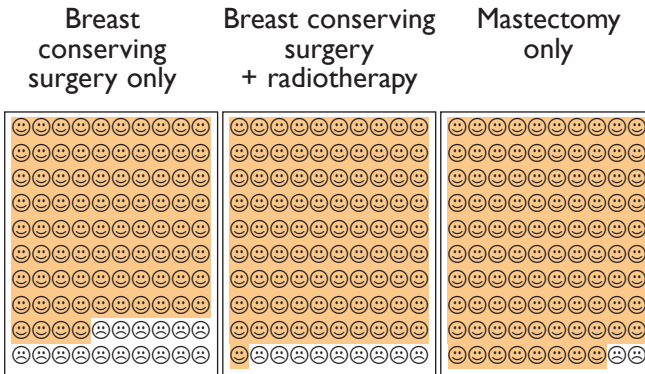
## How is DCIS treated?

DCIS is usually treated by surgery (breast conserving surgery or mastectomy), with or without radiotherapy. Hormonal therapies (drugs that change the way hormones work in the body) are still being tested for use in women with DCIS. Chemotherapy is not used to treat DCIS. *The treatments are explained in more detail in Chapters 4–6.*

## How successful are treatments for DCIS?

DCIS can be treated successfully, and most women treated don't develop invasive breast cancer. Treating DCIS greatly lowers your risk of developing invasive breast cancer but it does not remove this risk completely.

### Proportion of women who are free of DCIS or invasive breast cancer 4 years after treatment



- 😊 No DCIS or invasive breast cancer after 4 years
- ☹️ Developed DCIS again or invasive breast cancer within 4 years

Studies show that the number of women who are still free of DCIS and have not developed invasive breast cancer 4 years after treatment for DCIS are:

- 84 women out of 100 after breast conserving surgery alone
- 91 women out of 100 after breast conserving surgery and radiotherapy
- 98 women out of 100 after a mastectomy.

Only a few studies have looked at how long women with DCIS live after treatment.

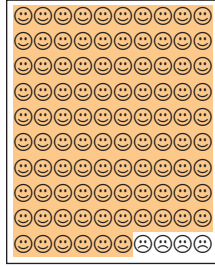
*See next page for long-term survival information.*

Every woman's situation is different. Treatment that is suitable for one woman might not be suitable for another.

**“It sounded almost like a relief because it didn’t sound as bad as a massive invasive tumour. It sounded containable.”**

**Your feelings Being diagnosed with DCIS could make you feel overwhelmed, scared, anxious or upset. These are all very normal responses. You might find it helpful to talk with your doctors about how you’re feeling. See Chapter 11 for details of information and support services.**

## Long-term survival of women treated for DCIS with breast conserving surgery and radiotherapy



😊 Alive after 15 years

😞 Died within 15 years

One study has shown that:

- 96 women out of 100 will be alive 15 years after treatment with breast conserving surgery and radiotherapy.

Comparable statistics for women treated with breast conserving surgery alone or with mastectomy are not available.



### Did you know?

About 1200 women are diagnosed with DCIS each year in Australia. Because DCIS cannot usually be felt as a breast lump or other breast change, most cases are found by routine screening with mammograms. Most women are not aware of any symptoms at the time of diagnosis.

DCIS can be found in women at any age, however, most women are between 50 and 69 years old when their DCIS is found.

DCIS can also develop in men although this is very rare.

## Diagnosis

This chapter explains:

- how DCIS is diagnosed
- what features of your DCIS are important.

### How was my DCIS diagnosed?

It's most likely that your DCIS was found after your doctor noticed small flecks of calcium (called microcalcifications) or some other abnormal area on your mammogram or ultrasound. Uncommonly, you or your doctor might have found a lump or lumpy area in your breast or you might have had bloody or clear fluid (discharge) coming from one nipple, which was investigated.

### Having a mammogram

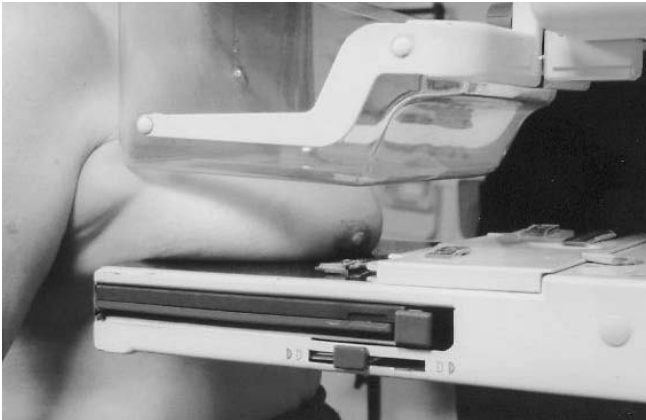


Photo courtesy of GP CBE Training Kit, NBCC

DCIS is confirmed by taking a biopsy (or sample of cells) from the abnormal area in your breast. You might have one or a combination of the following types of biopsies.

- A **fine needle aspiration (FNA)**, where a thin needle is used to remove some cells from the abnormal area.
- A **core biopsy**, where a wide needle is inserted into the abnormal area under local anaesthetic and a small amount of tissue is removed.

**“I was 50. I received my letter to go for a free mammogram and they found DCIS. I just felt cool, calm and collected.”**

“I was grateful that I got the letter to come for a mammogram because without it I probably still wouldn’t have gone to have one.”

- A **surgical biopsy** (sometimes called a hookwire-guided biopsy), where some of the abnormal tissue is removed under a general anaesthetic. Before surgery the radiologist may need to place a ‘marker’ in your breast to help the surgeon find the area of abnormal tissue. If all the DCIS is removed in your surgical biopsy, you might not need further surgery.

All three of these biopsies can be used to show whether there are abnormal cells in your breast. A core biopsy or surgical biopsy can be used to show whether the cells are DCIS or invasive breast cancer. FNA alone can’t tell the difference between DCIS and invasive breast cancer.

After any of these biopsies, or after breast surgery (*see Chapter 4*), the breast tissue or cells are sent to a pathologist. The pathologist examines the tissue or cells under a microscope and writes the results in a pathology report. Your doctor can explain what the report means and any words in it you don’t understand. You can ask your doctor for a copy of your pathology report to keep.

### What features of my DCIS are important?

Your doctors use your pathology report and mammograms or ultrasound to recommend the best treatment for you. They will also consider your age, whether you have a family history of breast cancer and your general health. This information helps your doctors work out how likely it is that your DCIS will come back, or that you will develop invasive breast cancer after treatment. *See table on page 8.*

The features of your DCIS that your doctors will consider are listed below. Some of this information will only be available after you have a surgical biopsy or breast surgery. *See Chapter 4.*

“I just couldn’t believe it, because I’ve never ever had a pain or an ache in the breast or anything.”

- **The size of the DCIS and where it is in your breast.** If the DCIS is in more than one area of your breast, it's called multicentric or multifocal DCIS.
- **Whether the surgical margin is clear or not.** During a surgical biopsy or breast surgery, the surgeon removes the abnormal area and some healthy looking breast tissue around it. The healthy looking breast tissue is called the surgical margin. If there are no DCIS cells at the edge of the healthy looking tissue, it's likely that all of the DCIS was removed from your breast. In this case, the surgical margin is said to be 'clear'. If there are DCIS cells at the edge of the healthy looking tissue, it's possible that not all the DCIS has been removed.
- The pathologist **grades the DCIS cells** as low grade (Grade 1), intermediate grade (Grade 2), or high grade (Grade 3). High-grade DCIS cells look more abnormal and grow faster than low-grade DCIS cells.
- Your report might show whether or not there are **hormone receptors** on your DCIS cells. Having hormone receptors means the growth of your DCIS is affected by hormones. This will affect whether hormonal therapy might be considered. *See Chapter 6.*

**“I was 57 when I was diagnosed with DCIS in three areas of my breast. Because my breast was small I had to have a mastectomy. I had an immediate reconstruction.”**

**“I was 56 and after a cluster of microcalcification was found on a mammogram I was diagnosed with DCIS. I had a lumpectomy and radiotherapy.”**

**Features that make it more or less likely that DCIS will come back or invasive breast cancer will develop after treatment**

“At 52 I had my regular mammogram and they found an irregularity that proved to be DCIS after a biopsy. I had breast conserving surgery and my surgeon said he got it all with clear margins as it was so small. He doesn’t think I’ll need radiotherapy but he’s referring me to a radiation oncologist for a second opinion.”

	It’s <b>less likely</b> that the DCIS will come back or invasive breast cancer will develop if:	It’s <b>more likely</b> that the DCIS will come back or invasive breast cancer will develop if:
<b>Size of the DCIS</b>	the area of DCIS is small	the area of DCIS is large
<b>Location of the DCIS</b>	the DCIS is in one area of your breast	the DCIS is in more than one area of your breast
<b>Grade</b>	the DCIS is low grade (Grade 1)	the DCIS is high grade (Grade 3)
<b>Surgical margin</b>	the surgical margin is clear	the surgical margin is not clear

Your age and whether you have a family history of breast cancer will also affect how likely it is that DCIS will come back or invasive breast cancer will develop. Your doctor will consider this together with your general health when recommending what treatment is best for you.

If one or more of the things listed in the ‘more likely’ column apply to you, it does not necessarily mean that your DCIS will come back or that you will develop invasive breast cancer after treatment.



# Deciding about treatment

This chapter explains:

- who is involved in your treatment
- how and when to decide about treatment.

Treatments for DCIS are described separately in Chapters 4–6.

## Who will be involved in my treatment?

Your treatment for DCIS will involve some or all of the following people:

- your **general practitioner (GP)** or **family doctor** who provides ongoing care and referrals to specialists
- a **surgeon** who does breast surgery and/or breast reconstruction surgery
- a **pathologist** who examines the cells/tissue removed from your breast under the microscope
- a **radiologist** who checks breast X-rays (mammograms) and ultrasound images
- a **radiation oncologist** who manages radiotherapy
- a **radiation therapist** who works the radiotherapy machines, under the direction of a radiation oncologist
- a **breast care nurse** who provides information and supportive care.

Although there will usually be several doctors and other health care professionals involved in your care and treatment, you will usually have one main point of contact for treatment. This person might change at different stages of your treatment. For example, at first your main contact might be your surgeon, but if you have radiotherapy this could later be your radiation oncologist.

There is evidence that care for women with invasive breast cancer is better when it is managed using a team approach. The same is likely to be true for women with DCIS. Your doctors and health care professionals will probably meet or talk with

# 3

## DECIDING ABOUT TREATMENT

**“My advice to other women going through the same thing I went through is to make sure you get a referral to a specialist breast surgeon and go to a treatment centre where they have a team approach.”**

**“I rang up the Cancer Council and they sent me out some brochures and my daughter got me lots of books all about it so I got plenty of reading information. I just asked the questions I needed to ask.”**

## **Making decisions**

**It's okay to take a week or two to decide about treatment. This can give you time to understand DCIS and choose the most appropriate treatment for you. However, it's not wise to take months to decide.**

each other to consider which treatments are best for you. One or more doctors will then discuss your treatment options with you.

Other health professionals who might be involved in your care include:

- a **counsellor, psychologist or psychiatrist** who gives emotional support and/or help in managing anxiety and depression
- a **social worker** who can arrange practical help (for example financial assistance, child care and help in the home)
- a **physiotherapist or occupational therapist** who provides information about exercises after surgery if they are necessary
- a **medical oncologist** who provides drug treatments, such as hormonal therapy, should it be necessary.

If you feel you would benefit from the services they provide, talk to your doctor about being referred to one of these health professionals. In rural and remote areas you might not have local access to the services of some of these health care professionals. Links to larger treatment centres by telephone or through visiting health professionals are possible.

## **Can I get a second opinion?**

If you don't feel comfortable with a particular doctor, or if you have questions that haven't been answered to your satisfaction, you can ask for a second opinion. A second opinion from another doctor with experience in DCIS and breast cancer can help you to feel reassured about your choice of treatment. If you want a second opinion, ask your specialist or your GP to refer you. You might decide, after seeing another doctor, that you want the first doctor to manage your treatment.

## **How do I decide about treatment?**

It's up to you how much you want to be involved in making decisions about your treatment. You might want to be actively involved or you might want your doctors to make decisions for you. Discuss any decisions you make with your doctors and

with those close to you. Ask for as much information as you need. You may need to contact your doctors or breast care nurse a few times before you make your decision.

### **Tips for talking to your doctors**

Receiving lots of new information can feel overwhelming. You might find some or all of these suggestions helpful:

- ask your doctors as many questions as you need, even if you have asked them before
- write down questions as you think of them, so you can remember to ask your doctor at your next visit
- ask a relative or friend to come with you when you visit your doctor
- if your doctor agrees, tape record your discussions so that you or your family can later listen to what the doctor said
- ask your doctor to give you a written summary of your treatment plan
- ask your doctor to refer you to a breast care nurse.

### **Using a professional interpreter**

If you are reading this book for a relative or friend who does not understand English very well, you can get a professional interpreter to help. A qualified interpreter can make sure that your relative or friend understands everything the doctor says. It might be hard for you to interpret some of the medical words, or you could feel upset by what is discussed. This could affect your ability to interpret everything that is said.

Interpreters are available in both public and private hospitals. They must be booked in advance. To book an interpreter:

- ask your doctor about the hospital's interpreter services
- call the Cancer Helpline on 13 11 20
- call the Translating and Interpreting Service on 13 14 50.

## **DECIDING ABOUT TREATMENT**

**“I don't know whether I was just afraid of asking questions because my doctor was extremely well-reputed and I thought he was excellent, but sometimes lines of communication just fell down.”**

**Getting Information**  
**It's important that you feel comfortable with your doctors, and get the support and information you need. Tell your doctors about any concerns and priorities you might have.**

**❓ Questions you might want to ask to help you decide about treatment**

- What treatment do you recommend? Why?
- What are the benefits, risks and side effects of each treatment option?
- What are the chances that DCIS will come back or breast cancer will develop after treatment?
- Can I speak with other women who have had this treatment?
- Can I work while I'm having treatment?

**“I really had to make the decision that was best for me – there wasn’t going to be any great answer on the Internet anywhere.”**

## Breast surgery

This chapter explains:

- what breast conserving surgery and mastectomy involve
- what to expect after breast surgery.

There are different types of breast surgery for DCIS. Most women with DCIS are treated with breast conserving surgery and radiotherapy. Another type of surgery that might be recommended is mastectomy. Sometimes, the surgical biopsy to diagnose DCIS is the only surgery needed because all the DCIS is removed by the biopsy.

The type of surgery your doctor recommends will depend on a number of things, including the size of the DCIS in relation to the size of your breast, the grade of your DCIS, your age and whether you have a family history of breast cancer. The risk that DCIS will come back or invasive breast cancer will develop is low following both types of surgery but is lowest for women who have a mastectomy (*see page 3*). Your doctor will discuss the benefits and risks of each type of surgery with you. The final decision will also be affected by any preference you have.

### Breast conserving surgery

Your doctor will usually recommend breast conserving surgery if the area of DCIS is small compared to the size of your breast. The DCIS with a surrounding area of healthy tissue is removed. The surgery will usually be done under general anaesthetic, although a local anaesthetic might be possible in some cases.

If you have breast conserving surgery you will be able to keep your breast, although it will not look the same as it did before. You will usually not need to wear a breast prosthesis or have a breast reconstruction (*see Chapter 7*). It is likely that you will have radiotherapy to the treated breast once your wound has healed (*see Chapter 5*).

**Breast conserving surgery is also known as a lumpectomy, conservative breast surgery, wide local excision or complete local excision (CLE).**

## What can I expect after breast conserving surgery?

Every woman's situation is different so it's not possible to say exactly what will happen after breast conserving surgery. Discuss this with your surgeon before your operation. You might also find it helpful speak to other women who have had breast conserving surgery. Some of the things that might happen are listed below.

### Usually after breast conserving surgery

- You will have a dressing (bandage) over the surgery site.
- You will have a scar on your breast. The position of the scar will depend on where the DCIS is in your breast and how much breast tissue is removed. The scar will become less noticeable with time.
- Your breast shape and size might change, depending on where the DCIS is in your breast and how much breast tissue is removed.
- You will feel some pain or discomfort in your breast while the wound is healing – this usually settles in a few weeks.

### Often after breast conserving surgery

- You will have a drainage tube in your breast, which will be removed a day or two after surgery. A drainage tube is used to drain any fluid that might collect in or around your scar (a seroma).

### Sometimes after breast conserving surgery

- You might have swelling, firmness and bruising around the wound in your breast. This usually settles in a few weeks. You might be given a compression dressing, called a binder, to help reduce bruising and swelling.
- You might have a numb area in your breast.

### Uncommonly after breast conserving surgery

- Your wound might bleed or become infected.
- Your wound might take a long time to heal.

**“My surgeon explained all the options I had.”**

Talk to your doctor or breast care nurse about any side effects you're concerned about or think you're developing. Most side effects can be managed with medical care.

### Will I need more surgery?

If there are abnormal cells in the area of healthy tissue around the DCIS removed from your breast, your surgeon might be concerned that not all the DCIS has been removed. In this situation, you will probably need to have more surgery to remove more breast tissue. Sometimes a mastectomy is recommended.

### Mastectomy

Mastectomy usually involves removal of the entire breast and nipple. The operation is done under general anaesthetic.

Your doctor might recommend that you have a mastectomy if:

- the area of DCIS is large compared to the size of your breast
- the DCIS and/or microcalcification is in more than one area of your breast
- after breast conserving surgery, the area of DCIS is larger than it appeared on the mammogram, or there are DCIS cells in the healthy tissue surrounding the DCIS (*see above*)
- the DCIS has come back in your breast and you had radiotherapy when you were first treated (radiotherapy can't be used again to treat the same breast).

Your doctor will also consider your age, family history of breast cancer, and your treatment preference.

If you have a mastectomy, you can have a breast reconstruction or wear a breast prosthesis (*see Chapter 7*). You might be able to have a breast reconstruction at the same time as the mastectomy. Ask your surgeon about this before your operation. You are very unlikely to need radiotherapy after mastectomy.

**“I was fine because I decided that it’s just a breast coming off and a lot less inconvenient than an arm or a leg. You don’t have to tell anybody you’ve had it.”**

“My surgeon said, ‘we can offer reconstruction at the same time’ and I started to come to terms with it.”

“They had a lady that came to the hospital. She was lovely. Apparently she goes out and talks to ladies who have had a mastectomy. She’s had one herself and she told me about it.”

## What can I expect after mastectomy?

Every woman’s situation is different so it’s not possible to say exactly what will happen after mastectomy. Discuss this with your surgeon before your operation. You might also find it helpful speak to other women who have had a mastectomy. Some of the things that might happen are listed below.

### Usually after mastectomy

- You will have a dressing (bandage) over the surgery site.
- You will have a scar that runs across your chest, which might become less noticeable with time.
- You will feel some pain, discomfort or numbness in your chest while the wound is healing. The discomfort usually settles in a few weeks but there will always be a numb area where the breast was.
- You will have a drainage tube in your breast, which will be removed a day or two after surgery. A drainage tube is used to drain any fluid which might collect in or around your scar (a seroma).

### Often after mastectomy

- You might feel a difference in weight between the two sides of your body, particularly if your other breast is large. The weight can be balanced using an external breast prosthesis, or with breast reconstruction. *See Chapter 7.*

### Sometimes after mastectomy

- You might have swelling and bruising around the wound in your chest. This usually settles with time. You might be given a compression dressing, called a binder, to help reduce bruising and swelling.
- You might feel like the breast is ‘still there’ but this feeling will usually disappear with time.

### Uncommonly after mastectomy

- Your wound might bleed or become infected.
- Your wound might take a long time to heal.



## The experience of having breast surgery

### How long will I be in hospital?

You will probably be admitted to hospital on the day of surgery. Breast conserving surgery usually takes less than an hour, while mastectomy might take a little longer. There will also be preparation time and time to recover from the anaesthetic. If you have a breast reconstruction at the same time as a mastectomy, the operation will take longer. *See Chapter 7.*

Breast conserving surgery for DCIS is typically done as a day procedure. If you have a mastectomy you will usually have a couple of nights in hospital. How long you stay in hospital will depend on your progress and whether there is someone to help you when you go home. If you have a breast reconstruction at the same time as a mastectomy, you will need to stay in hospital for longer. You might be discharged from hospital with drainage tubes in place. Your doctor or breast care nurse will tell you how to manage these.

### How long will I take to recover?

**Each woman is different in how long she takes to recover from breast surgery.**

Your wound should be ‘waterproof’ after a few days and fairly well healed after about a week. During the first few weeks, the area will be sensitive and need extra care. It will continue to heal and become stronger over time. If you have a breast reconstruction at the same time as a mastectomy, your recovery will usually be longer than after mastectomy alone.

Many women continue to feel tired and need to rest, even when their wound seems to have healed. You might find that you’re ready to return to work and/or your regular activities after a couple of weeks, or you might need longer.

Your physical recovery is important, but you will also need time to recover emotionally. *See Chapter 11.*

### Your feelings

**It is common to feel a sense of loss after breast surgery. You may feel uncomfortable about your sexuality, body and sense of self. Talk with your family, friends, doctors or breast care nurse about your feelings. Talking with other women who have had breast surgery can also be informative and supportive.**

## Surgery to remove lymph nodes

Women with invasive breast cancer usually have surgery to remove some lymph nodes (glands) from the armpit. This is because the lymph nodes in the armpit are usually the first place that invasive breast cancer cells will spread to, if they spread outside the breast.

**Because DCIS cells are contained within the milk ducts and do not spread into the breast tissue, most women with DCIS do not need to have lymph nodes removed from the armpit.**

Very occasionally, if the DCIS covers a large area of your breast or if the DCIS is high grade (*see page 8*) and widespread, your surgeon might be concerned that you could have some invasive breast cancer cells that have not been detected. In this situation, your surgeon might recommend removing some lymph nodes. If lymph nodes are removed from your armpit, you might experience one or more of the following side effects:

- numbness of your arm, shoulder, armpit and parts of your chest
- a seroma (an area of fluid that collects in the armpit after the lymph nodes are removed)
- shoulder stiffness
- a feeling of heaviness in your arm
- lymphoedema (swelling of an area of your body, such as the arm, breast or remaining breast tissue left on the chest after mastectomy, which can occur months or years after surgery); for more information about managing lymphoedema, visit [www.breasthealth.com.au/careafter/lymphoedema.html](http://www.breasthealth.com.au/careafter/lymphoedema.html) or contact the Cancer Helpline on 13 11 20.

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Talk to your doctor if you think you might be developing any of these side effects.

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**“I had very good family support and I had a very good positive attitude to everything but it did take me quite a long time to recover my full strength after the surgery. Emotionally it hit me fairly heavily and I probably didn’t even realise it at the time. Looking back I realise how much I was affected.”**

## ❓ Questions you might want to ask about breast surgery

- What is involved in each type of surgery? How much breast tissue will you remove?
- Where will the scar be and what will it look like?
- How long will I be in hospital, take to recover and need to be off work?
- Will I be able to drive, play sports or lift things after surgery?
- Who should I contact if side effects occur?
- How much will the surgery cost?
- If I have mastectomy, is breast reconstruction an option? Can it all be done in the same operation?
- Where and when can I get a breast prosthesis?

**“With DCIS you have to decide whether you want to have a mastectomy or a lumpectomy or whatever. It’s really up to you, and you need a lot of information and a lot of help to make that decision.”**

# 5

## RADIOTHERAPY

## Radiotherapy

This chapter explains:

- when radiotherapy is used
- what to expect with radiotherapy.

### What is radiotherapy?

Radiotherapy uses X-rays (controlled doses of radiation) to destroy DCIS and cancer cells. Having radiotherapy after breast conserving surgery lowers the risk that DCIS will come back or invasive cancer will develop in the treated breast by destroying any DCIS cells that may be left in your breast. *See page 3 for information about risk.*

### When is radiotherapy used?

Your doctors will usually recommend that you have radiotherapy after breast conserving surgery. However, if the area of DCIS in your breast is very small and low grade (*see page 8*) the likelihood of DCIS coming back or invasive breast cancer developing is lower. In this case, your doctors might not recommend radiotherapy. Radiotherapy is not generally used after mastectomy for DCIS.

### Who manages radiotherapy treatment?

A **radiation oncologist** manages radiotherapy treatment. He/she will tell you about the benefits and risks of radiotherapy and answer your questions.

### Radiotherapy treatment



Photo courtesy of The Picture Source Photographic Library

A **radiation therapist** works the radiotherapy machines, under the direction of the radiation oncologist.

### **What can I expect if I have radiotherapy?**

Usually you will start radiotherapy 8–12 weeks after surgery. Before you start radiotherapy, you will visit the radiotherapy centre, where your radiotherapy will be planned. Marks are put onto your skin so the radiation therapist knows where to direct the radiotherapy. These marks are small, and might be temporary, so you need to be careful not to wash them off during the treatment period. In some cases, the marks might be permanent (tattoo).

Once you start treatment, you will usually have radiotherapy once a day, 5 days a week (on weekdays), for 5–7 weeks. Each radiotherapy session will be in a treatment room, with a machine that looks like the one shown in the picture on page 20. The radiation therapist will leave the room while the machine is turned on, but he/she can still see and hear you.

Although each treatment only lasts about a minute, you will probably be in the treatment room for about 10 minutes. You might need to wait for the treatment room to become available, and you will also need time to change your clothes.

### **Where will I go to have my radiotherapy?**

Radiotherapy is available in some hospitals or specialised clinics in capital cities or major regional towns. Not all hospitals can provide radiotherapy. If you live outside a major city, some regional areas offer sessions with a visiting radiation oncologist who can discuss your treatment with you. Alternatively your GP or surgeon might discuss your treatment with the radiation oncologist on your behalf. However, you might need to travel to receive the radiotherapy.

Your surgeon, radiation oncologist, or GP will advise you of the nearest centres offering radiotherapy. If you need to travel long distances to a radiotherapy centre, you might be able to get

**Your feelings**  
**During**  
**radiotherapy**  
**treatment, if you**  
**feel upset or**  
**anxious, the**  
**therapist can turn**  
**the machine off**  
**and come back into**  
**the room.**

financial support to help you with travel and accommodation costs. *See page 49.*

### What are the side effects of radiotherapy?

Radiotherapy does not make you radioactive. Receiving radiotherapy is painless. However, you might have some discomfort, pain or other side effects as a result of treatment. Side effects can develop during treatment, or months after treatment has finished. The benefits of radiotherapy are usually considered to outweigh the risks of side effects.

Some of the things that might happen are listed below. This is not a complete list. **Talk to your radiation oncologist, radiation therapist, surgeon or breast care nurse about the possible side effects of radiotherapy.** They will explain how you can manage these side effects.

#### Usually after radiotherapy

- The skin on your breast will become red and dry, much like sunburn. This can begin from the second week of treatment, and usually improves a few weeks after completing treatment. *See page 23 for information about skin care during radiotherapy.*
- You will probably start to feel more tired than usual about a week or so after starting radiotherapy. This usually lasts for up to 4 weeks after completing treatment.
- Your skin can look darker than usual. It may stay that way for a few months after completing treatment, but the colour will fade with time.
- You will probably never be able to breastfeed from the treated breast. If you produce milk and are able to breastfeed from your treated breast, there is no evidence that this is unsafe for you or your baby. (You can safely breastfeed from your untreated breast.)

#### Sometimes after radiotherapy

- The skin on your breast might start to peel or blister towards the middle or end of your treatment. This usually settles within weeks of completing treatment.

**“I got tired that was all. I used to have the second-last or last appointment of the day because I was working but I’d come home and my husband would have tea ready for me. So I’d just relax then go to bed and start again the next day. My girls did all the housework.”**

- Your breast might feel tender, and you might feel occasional aches or twinges. This can continue for a year or more after stopping treatment, but the aches usually become milder and less frequent, and eventually settle with time.
- Your breast might become slightly swollen during treatment or some months after completing treatment. This usually settles with time (but it can take up to a few years).
- Your breast might become firmer during treatment or some months after completing treatment. This usually lessens with time, but your breast might be permanently firmer than it was before treatment.

#### **Uncommonly** after radiotherapy

- Blood vessels could become visible on small areas of the skin of your breast, making the skin in these areas look red or purple.
- You may develop a dry cough, mild fever, shortness of breath and tiredness. These are symptoms of inflammation of the lung (also called pneumonitis) and can develop up to 6 months after completing treatment. Talk to your radiation oncologist immediately if you develop these symptoms. Treatment is available, and pneumonitis usually lasts for less than a month.

#### **Very rarely** after radiotherapy

- Your ribs may be painful. There is a risk your ribs could fracture, due to the radiotherapy weakening your bones. Talk to your radiation oncologist immediately if you are experiencing rib pain.

### **Skin care during radiotherapy**

Radiotherapy can cause your skin to become more sensitive during treatment. The nursing staff can explain ways to look after your skin to reduce the damage from radiation and to make yourself more comfortable.

It's important to protect the skin in the treated area from physical or chemical damage during your course of treatment.

**“I had no fatigue. My skin was red and dry, but not at all sore or itchy. One month after the last treatment, my skin is almost normal again.”**

Examples of physical and chemical damage include rubbing the area or using deodorants or perfumes. You should also avoid extremes of temperatures around the treated area, such as hot water bottles or ice packs, and you should not expose the treated area to the sun.

During your course of radiotherapy, you can wash the treated area with a mild, unperfumed soap and gently pat the skin dry. Applying a light moisturising cream to the treated area can help to reduce skin reactions. Talk to your radiation oncologist or breast care nurse about which cream to use. If you develop a skin reaction, your breast care nurse or radiation oncologist will be able to give you dressings or creams to help reduce your symptoms.

After your radiotherapy is over and any symptoms have settled down you can go back to your normal skin care routine. However, it is suggested that you *always* protect the treated area from the sun.

### **? Questions you might want to ask about radiotherapy**

- Will I benefit from radiotherapy?
- When will I have radiotherapy? How long will I have radiotherapy for?
- Who should I contact if side effects happen?
- Will I be able to work while I'm having radiotherapy?
- Will I still be able to drive? Will I be able to drive myself to and from the radiotherapy centre?
- How much will radiotherapy cost me?
- Where will I go for radiotherapy?
- If I have to travel a long way to a radiotherapy centre, can I get any help with costs or accommodation?
- Is there any subsidised accommodation near the radiotherapy centre?



# Hormonal therapy

This chapter explains:

- what hormonal therapy is.

## What is hormonal therapy?

Hormonal therapy is a drug, usually in the form of a tablet, that changes the level of female hormones in the body or stops cells from being affected by hormones. There are several different types of hormonal therapy. In women with invasive breast cancer, hormonal therapies are used to stop the cancer cells from growing. They are only used in women who have hormone receptors on their cancer cells.

Hormonal therapies might be effective in women with DCIS. However, the long-term benefits and side effects of hormonal therapy for women with DCIS are not yet known. Clinical trials are continuing to test hormonal therapies for treating DCIS.

You might be offered hormonal therapy to treat your DCIS. This will depend on whether you have hormone receptors on your DCIS cells. It's important to weigh up the benefits and side effects of hormonal therapy for your situation. Ask your doctors about the side effects of hormone therapy.

# 6

## HORMONAL THERAPY

**Most of the evidence about hormonal therapy has come from women with invasive breast cancer. It is not yet known how much women with DCIS can benefit from hormonal therapy.**

# 7

## BREAST PROSTHESES AND BREAST RECONSTRUCTION

“I have a prosthesis. I got that about six weeks after the operation. The Breast Care Nurse at the hospital gave me a temporary one at the hospital and she gave me the forms to fill out to get a proper one.”

## Breast prostheses and breast reconstruction

This chapter is for women who have had or will be having a mastectomy. It explains:

- the advantages and disadvantages of a breast prosthesis
- the advantages and disadvantages of breast reconstruction.

### What is a breast prosthesis?

A breast prosthesis, or breast form, can be worn inside your bra to give shape to your clothes after a mastectomy. There are three main types of breast prosthesis.

- A **temporary prosthesis** is used for the first six weeks or so after surgery. It's very soft and light so it won't hurt while you're feeling sore. Usually, you'll be given a temporary prosthesis at the hospital. If not, phone the Cancer Helpline on 13 11 20.
- A **'permanent' prosthesis** is fitted when your mastectomy wound has healed. It's designed to match the skin tone, size and shape of your other breast. It's specially weighted so that it feels and moves like your other breast, restores your balance and helps prevent any posture problems.
- A **lightweight breast form** is specially designed for swimming and can be worn inside a swimming costume. Some breast forms are designed to stick onto the chest.

### Breast prostheses



Photo courtesy of Colleen's Post-Mastectomy Connection

## Do I need a new bra?

Many women like to wear a bra with a pocket in it to hold their breast prosthesis in place. You can buy special mastectomy bras, or you can sew a pocket into your regular bras. Ask about mastectomy bras and pockets when you are fitted for your prosthesis.

## Advantages and disadvantages of a breast prosthesis

If you choose to wear a breast prosthesis, when you're dressed, your shape can look similar to how it was before your surgery. However, you might not be able to wear some clothes (for example some low-cut or strapless tops or dresses).

You're likely to feel better about the way you look in clothes and other people won't be able to tell that you have had a mastectomy. Your posture and balance are likely to be more evenly weighted, particularly if your other breast is large, which means you're less likely to develop back and neck problems. However, a breast prosthesis can feel uncomfortable in hot weather.

Some women choose not to wear a prosthesis.

## Where can I get a breast prosthesis?

A temporary prosthesis will probably be given to you by the hospital after your operation. Permanent prostheses can be bought from some lingerie and department stores. It's important to get your prosthesis fitted by a specialist prosthesis fitter. Women tend to replace their breast prosthesis every 2–4 years.

## How much does a breast prosthesis cost?

The cost of your breast prosthesis will depend on the type you choose. If you're a public patient in a public hospital, you should be able to get your first prosthesis free of charge, or at a reduced cost. You might be eligible for a subsidy to meet the cost of your prosthesis through the state-based Program of Aids

**“I came home from hospital and I had a visit from a cancer volunteer. She brought me a soft prosthesis and explained where I could go for a proper one.”**

**Find out more**  
**For up-to-date information about different types of breast prostheses, where you can get a breast prosthesis, and how much a breast prosthesis costs, phone the Cancer Helpline on 13 11 20.**

for Disabled People. Talk to your breast care nurse or to a social worker to find out more.

If you have private health insurance, you might be able to get a refund for some or all of the cost of your prosthesis and/or mastectomy bras and pockets. Some health funds refund the cost of either a prosthesis or a breast reconstruction operation. To find out more, talk to your health fund advisor. Let your advisor know if you think you might want to have a breast reconstruction later.

### **What is a breast reconstruction?**

Breast reconstruction involves surgery to rebuild a breast shape using an implant or tissue from another part of your body (usually the back or stomach). It's also possible to have a nipple reconstruction, a nipple tattoo or to wear a false nipple/prosthesis if your nipple has been removed during surgery.

The type of breast reconstruction suitable for you will depend on a number of things, including your body shape, preference and general health. Talk to your surgeon about the different types of breast reconstruction, and which one is most suitable for you.

### **When can I have a breast reconstruction?**

Your breast reconstruction might be done at the same time as your mastectomy operation or it might involve another operation later. Talk to your surgeon about the timing of your breast reconstruction before your mastectomy operation. An immediate reconstruction might not always be possible.

If your breast reconstruction is done at the same time as your mastectomy, the operation will take longer. This could make it more difficult to have the surgery as soon as you'd like.

**There is no evidence that having a breast reconstruction makes it harder to find DCIS if it comes back or invasive breast cancer if it develops later.**

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Before deciding whether or not to have a breast reconstruction, consider the advantages and disadvantages of each type of procedure, and the importance of breast reconstruction to you.

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### **Advantages and disadvantages of breast reconstruction**

If you have a breast reconstruction, you won't need to wear an external prosthesis. You might also feel less grief about the loss of your breast and you might feel better about yourself and your body. Your weight will be more balanced so you are likely to have fewer back problems. However, you should bear in mind that although breast reconstruction aims to rebuild your breast so that it's as natural looking as possible, your reconstructed breast will not look and feel the same as it did before.

If you have a reconstruction, you'll need more surgery than if you had mastectomy alone and it will probably take you longer to recover from the operation. You might need another operation if there are any complications. This isn't common, but does happen for a small number of women.

Depending on the type of operation you have, possible side effects include: firmness of the breast mound; discomfort or pain; infection; or the need for the implant to be replaced later. If tissue from another part of your body is used, you may lose some muscle strength in that area, and you will also have scars on that part of your body.

### **How do I decide whether to have a reconstruction?**

If you are considering a breast reconstruction, it's important that you have a realistic expectation about what is involved and how your breast might look afterwards. Discuss this with your surgeon and other women who have had a breast reconstruction. Ask your surgeon to show you pictures of other women who have had similar breast reconstructions. The

**For more information about breast reconstruction call the Cancer Helpline on 13 11 20.**

**“They discussed reconstruction but I wasn't ready for that. I still think about it. If anything happened to the other breast I'd have reconstruction.”**

Cancer Helpline on 13 11 20 has other resources that might be useful, such as pamphlets and videos.

### **Surgery to the other breast**

Sometimes women having a breast reconstruction have surgery to the other breast as well, so that both breasts look the same.

This could mean a procedure to reduce, enlarge or change the shape of the other breast.

### **How long will I take to recover from breast reconstruction?**

The time it takes to recover from a breast reconstruction depends on the type of reconstruction. Usually women can get back to normal activities within 4–6 weeks after a reconstruction using an implant. Recovery after reconstruction using tissue from the back or stomach can take longer.

### **? Questions you might want to ask about breast reconstruction**

#### **Possibilities and outcomes**

- Is breast reconstruction possible for me? Which type do you recommend? Why?
- What will I look like after the reconstruction? Where will the scars be? Can you show me photographs of breasts you have reconstructed?
- Will I have any feeling in the reconstructed breast?
- Can you construct a nipple? How?

#### **The operation itself**

- What is involved in the breast reconstruction operation?
- How many operations will I need? How long will the operation take?
- Will you have to operate on my other breast?

**“When they did the reconstruction they augmented my right breast to match the new one.”**

- Who will perform the operation? Do you specialise in breast reconstruction?
- What side effects can I expect? Who should I contact if side effects happen?
- How long will I stay in hospital?
- How long will I take to recover?

### **Timing of breast reconstruction**

- What's the best time for my breast reconstruction – during the same operation as the mastectomy or later? Why?
- If I decide to have a breast reconstruction later, how long will I have to wait?
- If I decide not to have a breast reconstruction now, can I change my mind later?

### **Cost of breast reconstruction**

- How much will breast reconstruction cost?
- Is some or all of the cost covered by Medicare? By private health insurance?
- Will I have to pay for any costs 'up front', even if I can get money back later?

## Clinical trials

This chapter explains:

- what a clinical trial is
- advantages and disadvantages of taking part in a clinical trial.

### What are clinical trials?

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A clinical trial is research that aims to find better ways to prevent, diagnose, or treat diseases.

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Clinical trials assess whether promising new methods for disease prevention, diagnosis, and treatment are more effective than the current approaches. Clinical trials usually involve two groups of patients: those who receive the new treatment and those who receive the currently recommended treatment. If you agree to participate in a clinical trial, it is not possible to choose which treatment you receive.

### How do I decide whether to take part in a clinical trial?

Most trials are only suitable for some women, for example, women of a certain age, or who have had a particular treatment. If you are invited to take part in a clinical trial, you will need to weigh up the potential risks and benefits. You don't have to take part if you don't want to.

If you decide to take part in a clinical trial, you will be asked to sign a consent form. You can withdraw from the trial at any time.

If you decide not to take part in a clinical trial, or if you withdraw from one, you will receive the currently recommended treatments. **The quality of your care and treatment will not be affected.**

### Ethics approval

Clinical trials have to be approved by an ethics committee, to make sure that the rights of the patient are protected.



## Advantages and disadvantages of taking part in a clinical trial

If you take part in a clinical trial you might receive new treatments that are not yet available to the general public. The new treatments might or might not be more effective than the treatments currently recommended and they might have fewer or more side effects.

### For more information about clinical trials

- Ask your doctors about any clinical trials that are suitable for you.
- Visit the Australian and New Zealand Breast Cancer Trials Group website at [www.anzbcctg.org](http://www.anzbcctg.org).
- Visit the NHMRC Clinical Trials Centre website at [www.ctc.usyd.edu.au](http://www.ctc.usyd.edu.au).
- Visit The Cancer Council, NSW website at [www.cancercouncil.com.au](http://www.cancercouncil.com.au) for a list of breast cancer trials.
- Contact the Cancer Helpline on 13 11 20.

### 🔍 Questions you might want to ask about clinical trials

- What is the purpose of the trial? What are the advantages and disadvantages of taking part?
- How long will the trial last?
- What treatments or tests will I have if I am/am not involved in a trial? Have the treatments been used before to treat other cancers?
- What are the possible side effects of treatments or tests that I might have if I do/do not take part in the trial?
- Are there any costs involved if I take part in the trial?

# 9

## PREGNANCY AND MENOPAUSE

### Pregnancy and menopause

This chapter explains:

- what might happen if you are pregnant before, during and after treatment
- what to consider when managing menopausal symptoms.

#### Treatment during pregnancy

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Some treatments are not recommended if you are pregnant when diagnosed with DCIS.

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If you're already pregnant when your DCIS is diagnosed, you can have breast surgery with only a slight risk of miscarriage. The risk of miscarriage is lower after the first trimester. Discuss the timing of your breast surgery with your doctor.

Radiotherapy is not recommended if you are pregnant because it can harm your unborn baby. However, you can have radiotherapy after the baby is born.

#### Pregnancy during treatment

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It's recommended that you do not become pregnant while having treatment for DCIS.

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If it's possible that you could become pregnant before surgery or during the time you're having radiotherapy, it is recommended that you use non-hormonal contraception such as condoms or a diaphragm. It's unknown whether it's safe to take the oral contraceptive pill ('the pill') during or after treatment for DCIS. If you are unsure about what contraception to use ask your doctor.

## Pregnancy after treatment

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There is no evidence that it is unsafe for you to become pregnant after treatment for DCIS.

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If you become pregnant after you have completed treatment for DCIS, there is no evidence that the pregnancy will affect your risk of DCIS returning or getting invasive breast cancer.

## Menopause and HRT

Long-term use of combined hormone replacement therapy (HRT) can increase your risk of developing invasive breast cancer for the first time. The risk increases the longer you take HRT. For women who have already been diagnosed with DCIS, the risks from taking HRT are not known.

### **Managing menopause**

**A range of non-hormonal medications and lifestyle changes are used by women to manage the symptoms of menopause. Discuss the options for managing menopausal symptoms with your doctor and weigh up the benefits and risks of the different options for you.**

# 10

**FOLLOW-UP  
AFTER  
TREATMENT**

## Follow-up after treatment

This chapter explains:

- why follow-up is important
- what is involved in follow-up appointments.

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Regular follow-up is recommended after treatment for DCIS, and should be arranged through your doctor.

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Although treatment for DCIS lowers your risk of DCIS coming back or of invasive breast cancer developing in the treated breast, it does not remove the risk completely. You also have an increased risk of DCIS or invasive breast cancer developing in your other breast compared to women in the general population.

Regular follow-up means that if DCIS comes back or if invasive breast cancer develops it can be found and treated promptly. It also allows your doctors to manage any side effects you might develop from treatment and to give you emotional support.

**If you change doctors, ask your new doctor to request your medical records from your previous doctor.**

### What do follow-up appointments involve?

Appropriate follow-up after diagnosis and treatment for DCIS involves regular mammograms and breast examinations.

### Mammogram

**If you have had breast conserving surgery**, a mammogram on the same side as your surgery is recommended 6–12 months after treatment. Your doctor might recommend you have one earlier. A mammogram of both breasts is recommended once a year after that. Your mammogram should be arranged through your doctor rather than through a breast screening service.

### Your feelings

During your follow-up appointments, tell your doctors how you're feeling. There are many things your doctors can do to help you cope if you're having difficulties See *Chapter 11*.

**If you have had a mastectomy**, a mammogram of your other breast is recommended once a year.

### **Breast examination**

It is recommended that you have a physical examination of your breasts once a year after completing treatment. This is only a guide – your physical examinations could be more often than this.

Your doctor will examine both your breasts. If you have had a mastectomy your doctor will examine your chest and armpits.

### **What happens after follow-up appointments?**

If your doctor notices anything unusual in your mammogram or finds a lump or other breast change during your breast examination, you will need to have some more tests. This might include mammograms, ultrasounds or a biopsy.

If you find a change in your breast or nipple in between appointments, **do not wait until the regular appointment.** See your GP or specialist as soon as possible if you:

- feel a lump in either breast, or in the breast tissue left on your chest after mastectomy
- notice any changes in either breast, such as nipple discharge, nipple inversion or skin changes
- develop any other symptoms that concern you.

**“Emotionally the diagnosis and treatment had a huge impact because you’re always worried whether anything is going to resurface, if something had escaped.”**

**“I try not to anticipate things. If it comes back again, I’ll deal with it then. I don’t want to spend my life being frightened about the fact that it might come back. It might never come back.”**

# 11

## YOUR FEELINGS: COPING AND SUPPORT

### Your feelings

Being diagnosed with DCIS can change how you think and feel about things. Not all women feel the same way, but it can be reassuring to know that other women share some of the same experiences as you. It's not always easy, but over time, most women do cope with their experience and find they are able to return to doing the things that are important to them.

## Your feelings: coping and support

This chapter explains:

- how you might feel after being diagnosed with DCIS
- the impact your diagnosis and treatment might have on your partner, children, family and friends, and on other aspects of your life, including your sexuality
- how to find support to help you cope with your diagnosis and treatment.

### Dealing with difficult feelings

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Sharing your thoughts and feelings with others, even painful feelings, can help you cope with your diagnosis.

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Some of the feelings that have been reported by women diagnosed with DCIS are listed below. Most women find that, over time, these feelings ease.

- You might feel confused about what DCIS is. You might think “Do I have cancer or not?”. DCIS is *not* invasive breast cancer, and yet it's treated in a similar way.
- You might feel shocked and think “This can't be happening to me.” You might have a sense of disbelief or unreality.
- You might think “Why *me?*”. It's natural to feel anger, envy and resentment. Maybe you feel jealous of all the ‘healthy’ people you see, and resent that *you* have to cope with this diagnosis. Maybe you feel angry because you have lost some control over a part of your life or body, or maybe you feel angry with the way one of your doctors has managed your situation. Perhaps you feel angry about lack of support from a relative or close friend.
- You might feel you're being treated as a medical problem rather than as a *woman* with a medical problem. Sometimes doctors will pick up on your concerns, without you telling them. At other times, you might need to tell your doctor what you're worried about. Some women find that taking a friend or relative to appointments is helpful. If you feel your

concerns are not being recognised, you might decide you'd like to see another doctor. *See page 10.*

- You might feel alone or isolated. Sometimes people don't know how to deal with your diagnosis and the emotions it brings up. You could feel pressure to 'be positive', making it hard for you to talk about the things that matter to you. Maybe you feel isolated – it can be hard to explain your experience to others.
- You could find yourself asking "Where did I go wrong?" or "What have I done to deserve this?". However, getting DCIS is not within your control. There is nothing you have done to cause it.
- You might ask questions such as: "Am I living my life the way I want to?", "What is the meaning of life?", "Does God exist?". If you feel like this, you might find it helpful to talk to a friend, counsellor, psychologist or psychiatrist, or a religious leader or representative.
- Feeling sad or depressed is a common reaction to experiencing a loss, such as losing your breast, or being ill. You might feel your body has let you down.
- You might feel anxious or scared about your test results, your treatment and its effect on you and your family, or about the future.



Photo courtesy of The Valley Private Hospital

## YOUR FEELINGS: COPING AND SUPPORT

**“The radiologist told me you’re going to need surgery. I was absolutely devastated. All I could think of is I’m 40 years old, I have five young children – no, this is not happening to me.”**

**“I think you are aware of the fact that you can call your doctors and you can call the Breast Clinic because you know they are there if you want them, so it’s a backup.”**

**“I had lots of support from people in the neighbourhood but I was really, really depressed. I was scared stiff.”**

**“I try not to worry about little silly things now. You’ve got to get on with life. It’s no use sitting around worrying and moping because it affects you more then and you’ll end up doing nothing you want to do, being miserable.”**

## **Depression**

Women who have been depressed describe some or many of the following feelings:

- losing interest and pleasure in work or other activities
- feeling hopeless or worthless
- feeling guilty
- crying easily, being upset a lot, or feeling easily irritated
- not being able to laugh and see the funny side of things
- having difficulty sleeping
- feeling less interest in seeing family or friends
- being less motivated to organise or be involved in regular daily activities
- feeling ‘down’ a lot
- feeling overwhelmed by feelings, or feeling unable to control them.

Some women who have been depressed even feel that it is too hard to keep going, or feel suicidal. If you feel like this, talk to your doctor, breast care nurse or another health care professional. Treatment is available and can help.

## **Anxiety**

Women who are anxious describe some or many of the following thoughts or feelings:

- having worrying thoughts that interfere with your daily life or relationships
- feeling tense and finding it difficult to relax
- often feeling irritable or angry
- having difficulty concentrating or finding it difficult to make decisions
- having trouble sleeping
- getting sudden feelings of panic
- developing phobias or having phobias that become worse
- often avoiding distressing issues and situations.



If you are experiencing anxiety or fear that makes you feel overwhelmed, talk with your doctor, breast care nurse, or other health care professional as soon as possible. Treatment is available and can help.

### **Coping with depression and anxiety**

Here are some examples of help that is available if you are feeling anxious or depressed. Ask your doctors for more information. *See page 44* for other ways of finding support to cope with difficult feelings.

- **Talking** to a counsellor, GP, breast care nurse, social worker, psychologist or psychiatrist can be helpful.
- **Muscle relaxation therapy and imagery** (for example relaxation, meditation or yoga classes) can reduce stress in mild anxiety. Audio tapes can also help you relax.
- **Anti-depressants or anti-anxiety medication** can help you get through difficult times. You will usually only need to take medication for a short while, and there is no need to feel 'weak' or 'bad' if you need them to help you cope with this difficult experience. Talk to your doctors about any side effects that might occur.

### **The impact of your diagnosis and treatment**

#### **The impact on your sexuality**

Breast surgery and radiotherapy can affect how women feel about themselves and their attractiveness. This can happen whether or not the woman has a partner.

The changes to your body, how much energy you have, and your mood will affect how you feel about yourself. This includes your sexual desire and ability to be sexual with others. You might feel less attractive because of breast surgery and radiotherapy. Or your breast might feel tender after treatment.

### **YOUR FEELINGS: COPING AND SUPPORT**

**“It’s not the end of the world. Even though I lost a breast the DCIS hasn’t come back.”**

**“I know I can’t change what I stress about, but I can change me. I talk to my husband and my girls and I have another lady I can talk to so I don’t stress as much as I used to.”**

**Sharing your feelings can give others an opportunity to express their feelings and give you valuable support.**

## **Find out more**

**The National Breast Cancer Centre website [www.breasthealth.com.au/boysdocry](http://www.breasthealth.com.au/boysdocry) is a useful source of information and support for the male partners of women with breast cancer. Much of this information is also relevant for the partners of women with DCIS.**

There are ways of dealing with these problems. Some suggestions are listed below.

- Try to talk with your partner about each other's fears and needs. This will help you adapt to your situation and feel closer to one another.
- Ask for advice, either together or separately, from a specialist, such as a relationship counsellor, sex therapist, other counsellor, psychologist, or psychiatrist.
- It's common to have sexual concerns after treatment for DCIS. If you or your partner has concerns, try to discuss these with your doctor, nurse or other health care professional.
- If your doctor is unable to help you arrange a referral to a specialist, the Cancer Helpline on 13 11 20 can provide information about specialists.

### **For lesbian women**

You might feel that a lot of attention is placed on heterosexual couples, and that lesbian sexuality isn't mentioned when the effect of the diagnosis on sexuality is discussed. Some partners feel excluded, or even discriminated against.

Whether you tell your treatment team about your sexuality is up to you. However, if you feel comfortable with your team, telling them could help you feel more supported. If you don't feel comfortable with your treatment team, you might decide you'd prefer to see a different doctor or health professional.  
*See page 10.*

You might find that you get a lot of support from your partner, family, friends, or any social or other groups you're involved in. If you'd like to find out about support services specifically for lesbian women, contact your local women's health centre or the Cancer Helpline on 13 11 20.

## The impact on your partner, family and friends

Your DCIS diagnosis and treatment will affect the people who love you, such as your partner, your family and close friends. They might feel worried, powerless or not know what to say. They might feel similar emotions to you, such as shock, sadness, depression, fear, anxiety and anger. Everyone is different and will have their own way of coping with your diagnosis and treatment.

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Talk to your doctor, nurse or other health care professional if you're having any difficulties in your relationships, or if you feel that those close to you are not coping.

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Those close to you will probably have questions about your diagnosis and treatment. If you take your partner, a relative or close friend to your appointments with you, they can also ask questions. Or they might like to meet separately with your doctor. Your doctor will need your permission before discussing your medical situation with others. You might find it helpful to see a counsellor, psychologist or psychiatrist either together, or separately.

## The impact on your children

Your children are likely to be affected by your diagnosis. Depending on their age, they might know that something is wrong without you even telling them. Talk to your children about your diagnosis and treatment so they understand what is happening. Answer questions as honestly as possible in words they can understand. What they imagine to be happening could be more upsetting to them than the reality.

If you're concerned about your child's behaviour at school, you could tell the teacher about your DCIS, so that he or she understands any changes in behaviour.

Teenagers might feel particularly vulnerable as they try to cope with their own problems, as well as with your diagnosis and

## YOUR FEELINGS: COPING AND SUPPORT

**"I think it changed my attitude to life in general, that my mortality had been questioned and I became much more positive about doing things."**

**Find out more**  
**A good source of information and support for teenagers is the National Breast Cancer Centre website**  
**[www.myparentscancer.com.au](http://www.myparentscancer.com.au)**

**“I worry about my daughter. She came to me very upset because she’d found a breast lump.”**

treatment. They’re probably worried about how you’re coping and might take on more responsibility at home.

Your children might also worry about what your diagnosis means for them. It’s important to ask your children how they’re feeling and to recognise their distress. Letting them know you’re concerned and interested about their feelings will help them cope. If you’re worried about your children, you can ask your doctor to refer them to a counsellor, psychologist or psychiatrist. Or some or all of the family can see a family therapist.

### **Returning to work or your regular activities**

If you worked or were involved in a regular activity when you were diagnosed with DCIS, returning to this job or activity soon after treatment could make you feel valued and give you the comfort of being around people you’re familiar with. You might like to talk to your employer or organisation about making your hours more flexible for a period before, during and after treatment.

Some people find it difficult to talk with colleagues or friends about the experience of being diagnosed with DCIS. If you want to, share your experience with just a few close friends or colleagues. Sharing your feelings could give you valuable support.

### **Finding support to cope with your feelings**

There’s no ‘right way’ to find support and help. Some women find support from their partner, family and friends. Others express their feelings through writing, painting or dancing. Talking to other women who’ve been through a similar experience can be very helpful. The important thing to remember is that you don’t have to cope alone. If you live alone, or you don’t have supportive family or friends close by, you might find help from neighbours or from a local community group.

**“After my surgery I took six weeks off work and rested.”**



Photo courtesy of YWCA Encore

Some other suggestions for finding support are listed below.

- **Your doctor/s and other health care professionals** can provide emotional, psychological and practical support or can put you in touch with someone else who can help.
- **The Cancer Helpline** on 13 11 20 can provide confidential information about DCIS and related practical and support issues over the phone and in writing.
- **Breast Cancer Support Service (BCSS), Cancer Connect, or Cancer Council Connect** is a free and confidential service that can put you in contact with someone who has had the same treatments as you (although they might not have had DCIS). To access this service call the Cancer Helpline on 13 11 20.
- **Breast Cancer Network Australia (BCNA)** is a national network of women personally affected by breast cancer. Some of its members have experienced DCIS. BCNA seeks to improve care through advocacy, and the provision of information and targeted support. To contact BCNA call 1800 500 258 (toll-free) or (03) 9805 2500. Their website address is [www.bcna.org.au](http://www.bcna.org.au)
- **Other consumer groups** are available in each State and Territory. For more information call the Cancer Helpline on 13 11 20 or ask your breast care nurse.

## YOUR FEELINGS: COPING AND SUPPORT

**“I found it so reassuring to speak to another woman who had DCIS. She was six years ahead of me. I found it helpful to know about her recovery and all that sort of stuff.”**

**“I got most of my support from my doctor and my husband. My husband was just tremendous, he really was.”**

- **Counselling** can help you clarify your feelings and cope with them. You might receive some counselling from your treatment team. If not, or if you feel you'd benefit from further counselling, ask to be referred to a specialist, such as a counsellor, psychologist or psychiatrist. To find a counsellor, you can also contact your local community health centre, or phone the Cancer Helpline on 13 11 20.
- **Support groups and self-help groups** can help you share your concerns and fears with women in similar circumstances. You may want to investigate whether a group for women with DCIS exists in your area or you might find it useful to join a group for women with invasive breast cancer as the treatment you receive will often be similar. However, you should be aware that women with invasive breast cancer have different treatments and face different risks than you. To find out more, call the Cancer Helpline on 13 11 20 or contact your doctor, local hospital or local community health centre.

# Complementary therapies

This chapter explains:

- what complementary therapies are
- why it's important to tell your doctor about complementary therapies that you are taking.

## What are complementary therapies?

Complementary therapies are any treatments or therapies that are not part of your conventional treatment (such as surgery and radiotherapy).

### Examples of complementary therapies

- acupuncture
- relaxation therapy / meditation
- gentle exercise
- yoga
- tai chi
- positive imagery
- faith / spiritual healing
- laughter
- music
- megavitamins
- art
- massage
- aromatherapy
- dietary therapies
- some support group programs
- naturopathy
- immune therapy
- homeopathy
- Chinese herbs



Photo Courtesy of YWCA Encore

# 12

## COMPLEMENTARY THERAPIES

**Healthy living – including a good diet, exercise, enough sleep and relaxation, and effective management of stress – is important for everybody.**

Complementary therapies are used by some women in addition to their regular treatments. For example, relaxation therapy can reduce anxiety and feelings of pain. Exercising can help you to feel less tired, and can reduce your chance of weight gain. Gentle exercise, like walking, is ideal, but some women find that more strenuous exercise is also helpful. Check with your doctor about the level of exercise that might be suitable for you.

It's important to remember that many 'natural' or 'herbal' medications have not been proven to work or tested for side effects, or for their interactions with regular treatments.

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Some complementary medications might be harmful if taken at the same time as regular treatments. Talk to your doctors about any complementary therapies you are using or any other lifestyle changes you are making.

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### **? Questions you might want to ask a complementary health practitioner**

- What is the therapy you are proposing?
- How will it help?
- What is the evidence for the success of this therapy?
- What side effects could there be? How common are these?
- Will this therapy affect other treatments I am having?
- How much will this therapy cost?

Most specialists and GPs will discuss these therapies with you. For more information about complementary therapies visit the Australian government website [www.healthinsite.org.au/index.cfm](http://www.healthinsite.org.au/index.cfm) and click on 'Lifestyle' then 'Complementary and Alternative Therapies'.

**“I am a great believer that a good attitude and positive thinking helps healing and all sorts of things in living.”**



## Financial and practical support

# 13

**FINANCIAL  
AND PRACTICAL  
SUPPORT**

This chapter explains:

- how to get financial help during treatment
- how to get other practical help during treatment, such as childcare or other help at home.

### Costs of tests and treatments

The costs of your treatment will depend on: whether you are treated in the public or private system; whether you need to take time off work for treatment; and whether you need to travel for treatment. Discuss the likely costs of medical tests, treatment and support services with a member of your treatment team, such as your GP or social worker.

It might also be helpful to ask your pharmacist and/or local Medicare officer about the ‘safety net’ on medication costs and medical bills.

### Costs for public patients

You’re entitled to be treated for your DCIS as a public (Medicare) patient in a public hospital. You will be treated by doctors nominated by the hospital, and you will not be charged for most treatment and care costs. If some of your care isn’t paid for, extra financial help might be available. Talk to your breast care nurse or social worker (if you have one) about what financial help is available.

### Costs for private patients

If you have private health insurance, you can decide whether you want to be treated as a public or private patient. Make sure you tell your doctors what you decide.

It’s a good idea to find out how much your treatment will cost you before you start any treatment as a private patient. Ask your doctor for a quote, and talk to an advisor from your health fund.

You might want to ask the advisor from your fund about some or all of the following:

- Which treatments and services are covered by my insurance?
- Which treatments and services are not covered by my insurance?
- If I claim for a particular treatment or service now, does this mean that I cannot claim for other treatments or services later on? (For example, some health insurance policies might pay for either a breast prosthesis or a breast reconstruction, but not for both).
- What is the gap between treatment or service costs and the private medical insurance rebate? That is, how much of the treatment or service cost will I need to pay?

If you prefer, you can choose to pay for treatment as a private patient, even if you don't have private health insurance. Talk to your doctors if you'd like to find out more about the costs.

### **Accommodation, travel and other practical help when having treatment**

If you need treatment such as surgery or radiotherapy in a centre or hospital that is far from where you live, accommodation might be available for you and your family at a reduced cost. You might also only have to pay some of the travel costs.

Depending on your situation and where you live, financial and practical help might also be available for child care, meals and general home help.

You could also be eligible for a sickness allowance while you're having, and recovering from, treatment.

To find out about financial assistance and practical help, start by asking your breast care nurse, hospital or community social worker, or community nurse. He/she can help you to claim the benefits that might be available.

You can also contact the Cancer Helpline on 13 11 20 for information. Some local councils also help with practical matters, such as child care, meals and general home help.

## The Internet

In addition to the information you receive from your treatment team, you might find information from different sources helpful. Throughout this book, we recommend that you phone the Cancer Helpline on 13 11 20 for relevant, up-to-date, local information.

‘Surfing’ the Internet can also be a useful way to find information. However, keep in mind that the information you find might not always be accurate. Use careful judgement, and check what type of organisation has put the information on the Internet. Also, the information you’re looking for may not be found easily. It is important to make sure that the information you’re reading is about DCIS and not invasive breast cancer.

If you don’t have Internet access at home, the Internet can be accessed at local libraries and in Internet cafés. If you aren’t able to access the Internet, you can ask the Cancer Helpline on 13 11 20 to print out information from websites and send it to you.

**There are many Internet sites about cancer and breast cancer. You might also like to ask your doctor about other Internet sites that could be suitable for you.**

**\*Please note that some of the information on websites from other countries might only apply to people in that country.**

Some Australian websites that you might find helpful are:

### **National Breast Cancer Centre**

**[www.breasthealth.com.au](http://www.breasthealth.com.au)**

This website has up-to-date information about DCIS and invasive breast cancer. Through it you can also access the **National directory of hospital based services for women with breast cancer** where you can find out what treatments and services are available at your local hospitals.

### **Breast Cancer Network Australia**

**[www.bcna.org.au](http://www.bcna.org.au)**

This website has personal stories written by women with invasive breast cancer, and practical suggestions and resources. As some of the treatments are the same, you could find the stories and information helpful.

### **The Cancer Council Victoria**

**[www.accv.org.au](http://www.accv.org.au)**

This website has information developed by the Cancer Council Victoria, including information about DCIS and invasive breast cancer. It also has links to other State and Territory Cancer Councils.

Some websites from other countries\* that you might find helpful include:

### **American Cancer Society (USA)**

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

This gives information about cancer, including DCIS and breast cancer. The site also has information about the society itself, its publications and programs.

### **CancerBACUP (UK)**

**[www.cancerbacup.org.uk/info/dcis.htm](http://www.cancerbacup.org.uk/info/dcis.htm)**

This is the UK's leading cancer information service.

### **National Cancer Institute (USA)**

**[www.cancer.gov](http://www.cancer.gov)**

This information is developed by the National Cancer Institute in the USA for health care professionals, cancer researchers and the general public. The site provides information about DCIS under the heading of breast cancer.

### **OncoLink (USA)**

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

This site is sponsored by the University of Pennsylvania Cancer Centre, USA. It has information about DCIS and invasive breast cancer.

## Disclaimer

Information in this book is based on evidence in *The clinical management of ductal carcinoma in situ, lobular carcinoma in situ and atypical hyperplasia of the breast*, endorsed by the Breast Cancer Network Australia, The Cancer Council Australia, Royal Australian and New Zealand College of Radiologists, the Royal Australasian College of Surgeons and The Royal College of Pathologists of Australasia.

For more information about the evidence in this book see the following, produced by the National Breast Cancer Centre:

- *The clinical management of ductal carcinoma in situ, lobular carcinoma in situ and atypical hyperplasia of the breast*
- *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer.*



Proudly supported by



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