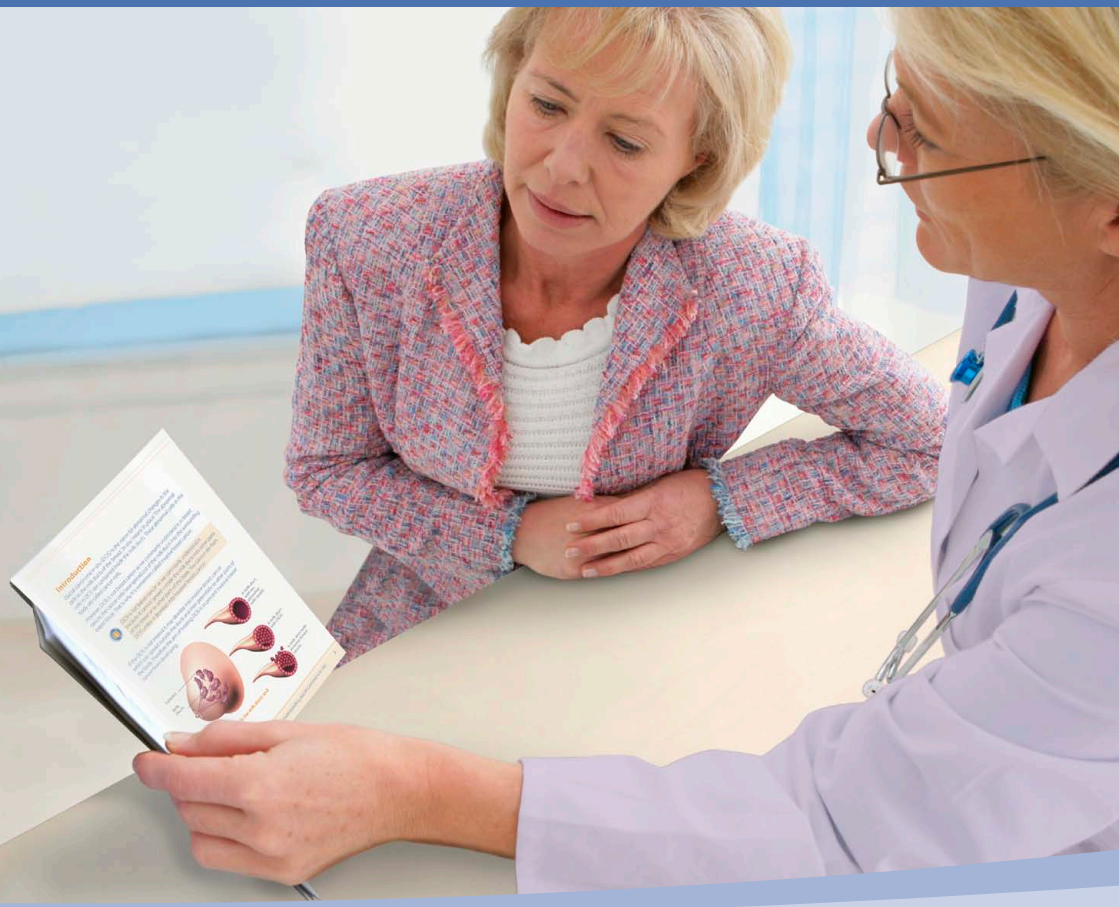
Understanding ductal carcinoma in situ (DCIS)



and deciding about treatment

NATIONAL BREAST AND OVARIAN CANCER CENTRE

Understanding ductal carcinoma in situ (DCIS) and deciding about treatment

Developed by National Breast and Ovarian Cancer Centre

Funded by the Australian Government Department of Health and Ageing

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ISBN Print: 978-1-74127-149-2 Online: 978-1-74127-150-8 CIP: 616.99449

Copies of this booklet can be downloaded from the National Breast and Ovarian Cancer Centre website: www.nbocc.org.au or ordered by telephone: 1800 624 973.

Recommended citation

National Breast and Ovarian Cancer Centre. Understanding ductal carcinoma in situ. National Breast and Ovarian Cancer Centre, Surry Hills, NSW, 2009.

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National Breast and Ovarian Cancer Centre is funded by the Australian Government Department of Health and Ageing.

Contents

Acknowledgements

This communication aid was developed by Simone De Morgan in collaboration with the Centre for Medical Psychology & Evidence-based Decision-making, University of Sydney on behalf of National Breast and Ovarian Cancer Centre. Illustrations undertaken by Rodney Lochner.

We gratefully acknowledge the support of the many women and health care professionals who provided valuable input into development of this resource.

How to use this resource

Understanding ductal carcinoma in situ communication aid is designed to assist clinicians to communicate with women diagnosed with DCIS to improve their understanding about their diagnosis, prognosis, treatment and support.

The aid is designed to be used with the woman during the consultation then given to the woman to take home as an information resource. **This aid is not designed to be a stand alone information resource for women**.

The order in which you use the diagrams and information will depend on whether you are using the aid in the initial diagnostic consultation, in a pre-operative consultation or a post-operative consultation. **You do not need to use every page of the aid and you do not need to use all diagrams and information on the pages that you use in the aid.**

You may **circle** the relevant features of the woman's DCIS in the diagrams of weighing scales on pages, 9, 10 & 11 if you find this useful.

You may **circle** the woman's risk category for recurrence: lower, intermediate and higher risk; and **tick the boxes** for relevant features associated with lower and higher risk on pages 13, 14 & 15 if you find this useful.

Introduction

Ductal carcinoma in situ (DCIS) is the name for abnormal changes in the cells in the milk ducts of the breast. 'In situ' means 'in place'. The abnormal cells in DCIS are contained inside the milk ducts. These abnormal cells in the body are called cancer cells.

However, DCIS is not breast cancer as we commonly understand it. In breast cancer, the cancer cells have spread out of the milk ducts into the surrounding breast tissue. That is why it is sometimes called 'invasive' breast cancer.

DCIS is not breast cancer as we commonly understand it because it cannot spread outside the milk ducts into other parts of the breast or to other parts of the body. You cannot die from DCIS unless it develops into 'invasive' breast cancer.

If the DCIS is not treated it may develop into invasive breast cancer which can spread outside the ducts and then potentially to other parts of the body. Therefore the aim of treating DCIS is to prevent invasive breast cancer from developing.

A woman's breast with the milk ducts and lobules (milk sacs)

Why do I need treatment for DCIS?

It is not reliably known the percentage of women with DCIS who would develop invasive breast cancer if they were not treated.

Also, it is not possible to predict which women with DCIS will develop invasive breast cancer if they were not treated or how long after the diagnosis of DCIS an invasive breast cancer would develop. In other words, some women with DCIS may never develop any problems if they are not treated. However, some women with DCIS may develop invasive breast cancer.

Current research aims to help health professionals better predict which women with DCIS will develop invasive breast cancer and how long after the diagnosis of DCIS this would occur.

Because DCIS may develop into invasive breast cancer and invasive breast cancer can spread and cause death, all women with DCIS are recommended to have treatment. Treatment for DCIS aims to help prevent invasive breast cancer from developing and DCIS from coming back in the breast.

DCIS can be treated successfully and most women diagnosed and treated for DCIS will not later develop invasive breast cancer.

Treatment for DCIS

Treatment for DCIS may involve:

1. Surgery

Treatment for DCIS usually involves surgery. The goal of surgery is to remove the area of DCIS. Surgery involves either breast conserving surgery (lumpectomy) or a mastectomy. See page 7 for more details.

2. Radiotherapy

Treatment after breast conserving surgery usually involves radiotherapy. The goal of radiotherapy is to destroy any abnormal cells that may be left in the breast after surgery. Radiotherapy is not recommended after a mastectomy because the risk of developing invasive breast cancer is very small. See page 11 for more details.

3. Hormonal treatments

Hormonal treatments, for example, Tamoxifen, **may be considered** for women with DCIS after surgery. Hormonal treatments may decrease the risk of developing invasive breast cancer in both breasts. This is an area of current research. The benefits of hormonal treatments need to be weighed against the side effects for each woman's particular situation. Talk to your doctor to see if this is an option for you.

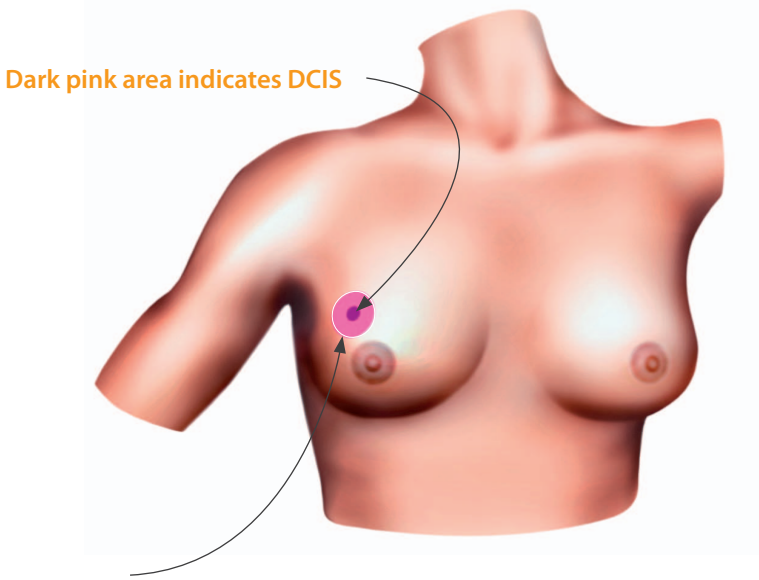
Chemotherapy is not useful in the treatment of women with DCIS because the abnormal cells have not spread out of the milk ducts.

It is important to be informed before you make a decision about treatment. Take some time to find out about the treatment options and what the best course is for you.

Surgery

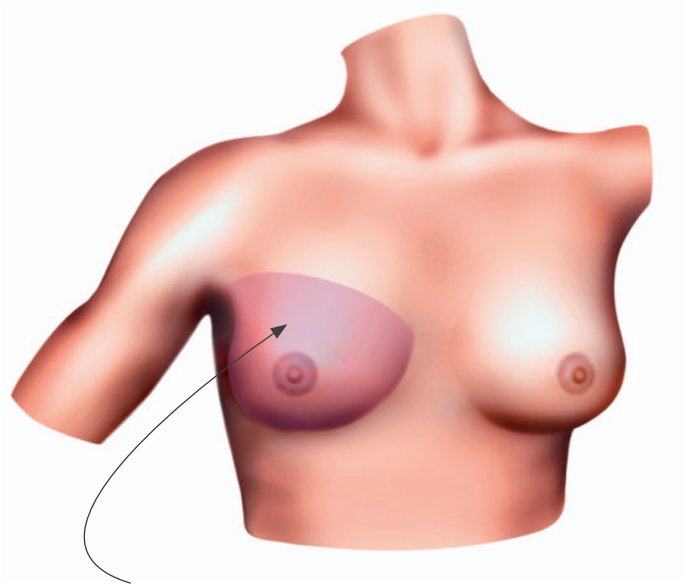
Option 1: Breast conserving surgery with or without radiotherapy

Most women with DCIS are treated with breast conserving surgery with radiotherapy. **Breast conserving surgery** means that a woman's whole breast is **not** removed. Breast conserving surgery removes the area of DCIS plus a small area of healthy breast tissue around the DCIS (called the 'surgical margin'). Breast conserving surgery is sometimes also called a **lumpectomy**. Usually lymph nodes under the armpits, which drain fluid from the breasts, do not need to be removed as DCIS does not spread outside the breasts.



Option 2: Mastectomy

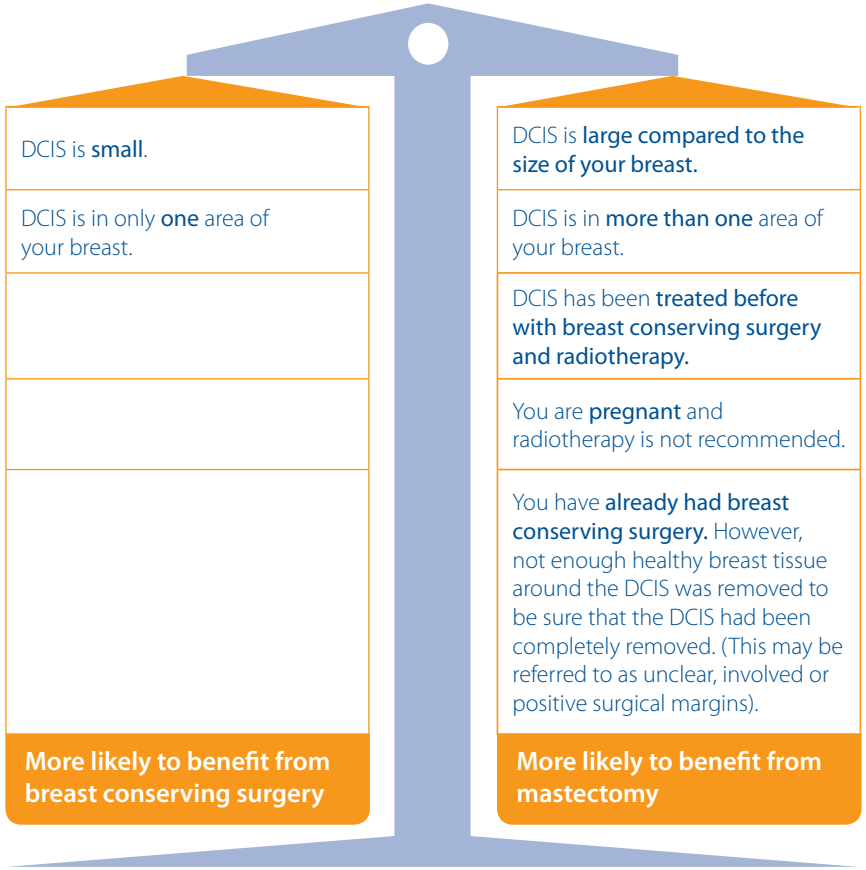
Mastectomy means surgery to remove a woman's whole breast, including the nipple. Usually lymph nodes under the armpits, which drain fluid from the breasts, do not need to be removed as DCIS does not spread outside the breasts. **Breast reconstruction** (at the time of the mastectomy or some time later) is almost always an option. Women not wanting to have breast reconstruction can wear a **prosthesis** (a breast form that can be removed and is worn under clothes to give a natural looking shape).



Pink area indicates breast tissue removed during surgery

Would I benefit more from breast conserving surgery or a mastectomy?

Doctor to circle relevant features

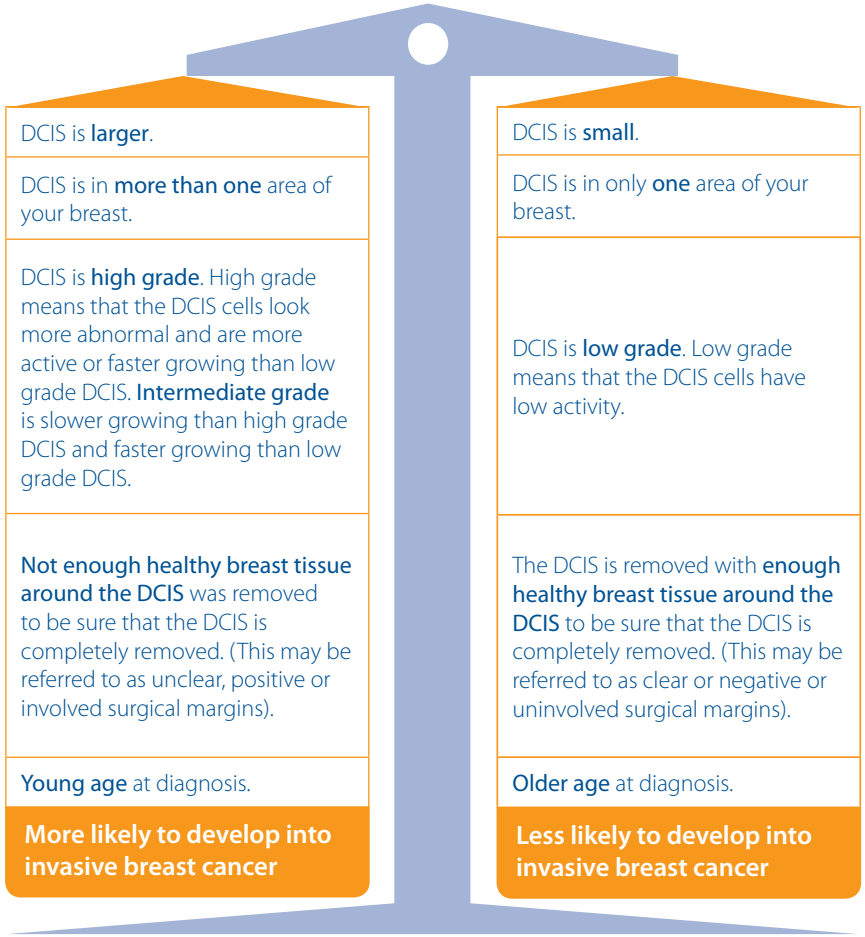


To help you decide about whether to have breast conserving surgery or a mastectomy, you will also need to discuss with your doctor the side effects of the different types of surgery. This information is not included in this booklet.

What features of your DCIS make it more or less likely to develop into invasive breast cancer?

Your pathology report after a breast biopsy and after surgery will tell you and your doctor the features of your DCIS. **Even if you have all the features listed on the left, you may never develop invasive breast cancer.**

Doctor to circle relevant features



More likely to develop into invasive breast cancer	Less likely to develop into invasive breast cancer
DCIS is **larger**.	DCIS is **small**.
DCIS is in **more than one** area of your breast.	DCIS is in only **one** area of your breast.
DCIS is **high grade**. High grade means that the DCIS cells look more abnormal and are more active or faster growing than low grade DCIS. **Intermediate grade** is slower growing than high grade DCIS and faster growing than low grade DCIS.	DCIS is **low grade**. Low grade means that the DCIS cells have low activity.
Not enough healthy breast tissue around the DCIS was removed to be sure that the DCIS is completely removed. (This may be referred to as unclear, positive or involved surgical margins).	The DCIS is removed with **enough healthy breast tissue around the DCIS** to be sure that the DCIS is completely removed. (This may be referred to as clear or negative or uninvolved surgical margins).
Young age at diagnosis.	**Older age** at diagnosis.

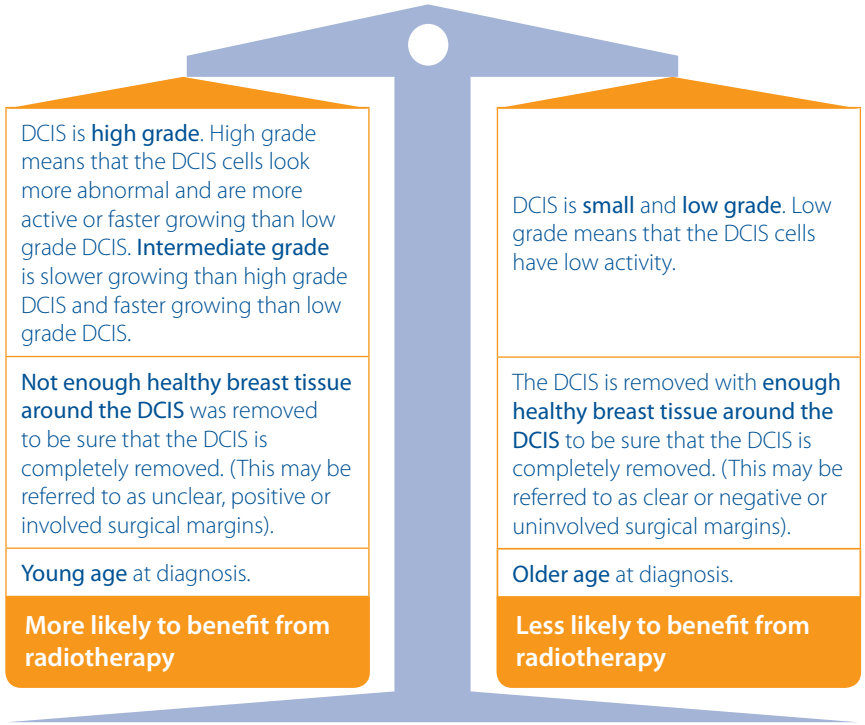
Radiotherapy

Radiotherapy is often recommended after breast conserving surgery. Radiotherapy is not needed after a mastectomy. Radiotherapy uses X-rays (low doses of radiation) to destroy any abnormal cells that may be left in a woman's breast after surgery.

Radiotherapy decreases the risk of developing invasive breast cancer and DCIS again by at least half.

Would I benefit from radiotherapy

Doctor to circle relevant features



More likely to benefit from radiotherapy	Less likely to benefit from radiotherapy
DCIS is **high grade**. High grade means that the DCIS cells look more abnormal and are more active or faster growing than low grade DCIS. **Intermediate grade** is slower growing than high grade DCIS and faster growing than low grade DCIS.	DCIS is **small** and **low grade**. Low grade means that the DCIS cells have low activity.
Not enough healthy breast tissue around the DCIS was removed to be sure that the DCIS is completely removed. (This may be referred to as unclear, positive or involved surgical margins).	The DCIS is removed with **enough healthy breast tissue around the DCIS** to be sure that the DCIS is completely removed. (This may be referred to as clear or negative or uninvolved surgical margins).
Young age at diagnosis.	**Older age** at diagnosis.

To help you decide about whether to have radiotherapy, you will also need to discuss with your doctor the side effects of radiotherapy. This information is not included in this booklet.

What is the risk of developing invasive breast cancer or DCIS after treatment?

Your risk of developing invasive breast cancer or DCIS after treatment[1] is a: *Doctor to circle risk category:*

- **lower risk**
- **intermediate risk**
- **higher risk**

If you are at lower risk see page 13. If you are at higher risk see page 14 and 15. If you are at intermediate risk your risk is between lower and higher risk.

Your doctor may not know all the features of your DCIS if you have not yet had surgery. After surgery your doctor will be better able to determine your risk.

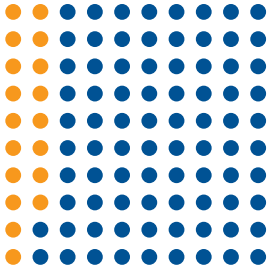
Lower risk

You may have a lower risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick box for relevant features see page 9 for more details

- ☐ a small area of DCIS (less than approximately 1.5cm)
- ☐ DCIS is in only one area of your breast
- ☐ you have low grade DCIS
- ☐ you have clear and adequate surgical margins (greater than or equal to approximately 1cm)
- ☐ you have been diagnosed at an older age (greater than 60 years old).

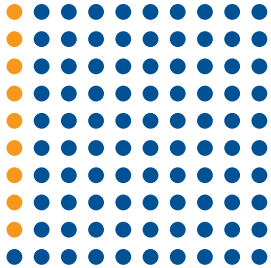
What is the risk after breast conserving surgery without radiotherapy?[2]



100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is about 18%. In other words, about 18 women out of 100 women will develop invasive breast cancer or DCIS and 82 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?[2]



100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is approximately 9%. In other words, approximately 9 women out of 100 women will develop invasive breast cancer or DCIS and 91 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

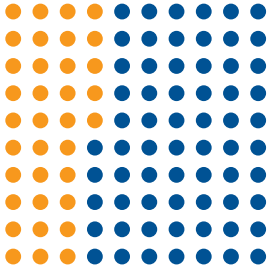
Higher risk

You may have a higher risk of developing invasive breast cancer or DCIS after treatment if you have:

Doctor to tick relevant features see page 9 for more details

- ☐ a larger area of DCIS (greater than approximately 4cm)
- ☐ DCIS is in more than one area of your breast
- ☐ you have high grade DCIS
- ☐ you have unclear or inadequate surgical margins (less than 1mm margin)
- ☐ you have been diagnosed at a younger age (less than 40 years old).

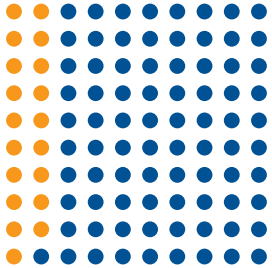
What is the risk after breast conserving surgery **without** radiotherapy?[2]



100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is about 35%. In other words, about 35 women out of 100 women will develop invasive breast cancer or DCIS and 65 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after breast conserving surgery **with** radiotherapy?[2]

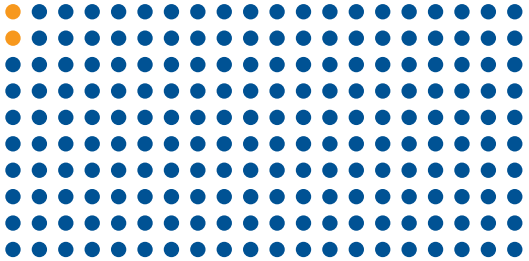


100 women

The overall risk of developing **invasive breast cancer** or **DCIS** in the same breast is approximately 19%. In other words, approximately 19 women out of 100 women will develop invasive breast cancer or DCIS and 81 women won't develop invasive breast cancer or DCIS. About half of the problems that develop are due to invasive breast cancer.

What is the risk after a mastectomy?[3]

There is still a very small risk of developing DCIS or invasive breast cancer in the small amount of breast tissue left after a mastectomy.



200 women

After a mastectomy for DCIS: (figures include lower and higher risk)

The risk of developing **invasive breast cancer** in the small breast tissue that is left is less than 1% and your risk of developing **DCIS** is less than 1%. In other words, after mastectomy, 1 woman out of 200 women will develop invasive breast cancer and 1 woman out of 200 women will develop DCIS.

What is the risk of developing invasive breast cancer in the general population in Australia?

If all Australian women lived to the age of 85 years, then one in 8 women would develop **invasive breast cancer** during their lifetime. This includes women who have been diagnosed with DCIS and women who have not been diagnosed with DCIS. In other words, approximately 13 women out of 100 women will develop invasive breast cancer during their lifetime, if all women lived to the age of 85 years.

The risk of developing **invasive breast cancer** in the opposite breast for women who have been diagnosed with DCIS is twice the risk of women in the general population.

What follow-up will I need?

Your surgeon, radiation oncologist, medical oncologist and/or GP will do regular check-ups of your breast and discuss the side effects of any treatments you have had. Regular check-ups involves mammograms each year and regular physical examination of your breasts for abnormal lumps.

Regular check-ups means finding any abnormal changes in your breasts and treating them early.

How can I get more emotional support?

It is common for women to feel shocked, anxious, depressed or have concerns after a diagnosis of DCIS. Coping with the uncertainty about whether you may develop invasive breast cancer or whether the DCIS may come back, and coping with treatments, can be difficult.

Sharing your thoughts and feelings with your family and friends, your GP, your surgeon, your breast care nurse or a counsellor/psychologist can help you cope with your diagnosis.

Help is available if you need it. You don't have to cope alone. Don't put up with any feelings that you feel overwhelmed by.

Ask your GP to refer you to a breast nurse, counsellor, psychologist or psychiatrist if you feel you would benefit from more support.

You may also call the **Cancer Council Helpline** on **13 11 20** for more information and support. Staff on the Cancer Council Helpline can talk with you confidentially about your feelings and concerns and may be able to refer you to a support group in your area.

Support groups hold regular meetings for people in similar circumstances to talk about their experiences and to share their concerns. There may be support groups for women with DCIS in your area. If not, there are many support groups for women with invasive breast cancer. These women will have similar treatments to you (apart from some women with invasive breast cancer who will have chemotherapy).

Support may also be available from *(doctor to insert if appropriate)*:

_____

Phone number:_____

References

1. Silverstein MJ, The University of California/Van Nuys prognostic index for ductal carcinoma in situ of the breast. Am J. Surg. 2003; 186(4):337-43.
2. Bijker N, Meihnen P, Johannes LP, et al. Breast-conserving treatment with or without radiotherapy in ductal carcinoma in situ: ten-year results of European Organisation for Research and Treatment of Cancer randomized phase III trial 10853 – a study by the EORTC Breast Cancer Cooperative Group and EORTC Radiotherapy Group. JCO. 2006; 24(21):3381-87.
3. Boyages J, Delaney G and Taylor R. Predictors of local recurrence after treatment of ductal carcinoma in situ. Cancer. 1999. 85:616-28.

You may like to write your own questions here:

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