

Understanding

Cancer of the Breast

Caring for people with cancer



Understanding

Cancer of the Breast

This booklet has been written to help you understand more about breast cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on breast cancer, its treatment and how it may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information that you may need.



| | Name | Telephone |
|-----------------------|------|-----------|
| Specialist nurses | | |
| Family doctor (GP) | | |
| Surgeon | | |
| Medical oncologist | | |
| Radiation oncologist | | |
| Oncology day ward | | |
| Radiation therapist | | |
| Medical social worker | | |
| Emergency | | |

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

BREAST CANCER ADVISERS

Elizabeth Connolly, Consultant Breast Surgeon
Yvonne Hanhauser, Advanced Nurse Practitioner

CONTRIBUTOR

Susan O'Carroll, Cancer Nurseline Nurse

EDITOR

Sarah Lane

The following sources were used in the publication of this booklet:

- *National Breast Cancer GP Referral Guidelines*. National Cancer Control Programme (NCCP), 2009.
- *Development of Services for Symptomatic Breast Disease: Report of the Sub-Group to the National Cancer Forum*. Department of Health and Children, 2000.
- *Follow-Up Care Plan after Treatment for Breast Cancer: A Guide for General Practitioners*. National Cancer Control Programme, July 2012.
- *Cancer in Ireland 2011*. National Cancer Registry Ireland, 2011.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (editor), 9th edn. Lippincott Williams & Wilkins, 2011.
- *Reducing the Risk of Upper Limb Lymphoedema*. Royal College of Nursing, 2011.
- *The Chemotherapy Source Book*. M Perry. Lippincott Williams and Wilkins, 1997.

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society 1998, revised 2003, 2006, 2008, 2009, 2011, 2012, 2014, 2017

Next revision: 2019

Product or brand names that appear in this book are for example only. The Irish Cancer Society does not endorse any specific product or brand.

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

ISBN 0953236901

Contents

4 Introduction

About breast cancer

- 5 What is cancer?
- 6 What are the breasts?
- 6 What is breast cancer?
- 7 What are the types of breast cancer?
- 10 How common is breast cancer?
- 10 What increases my risk of breast cancer?
- 12 Being diagnosed with breast cancer
- 13 What tests will I have?
- 16 Staging and grading breast cancer
- 18 Asking about your prognosis

Treatment and side-effects

- 19 How is breast cancer treated?
- 24 Surgery
- 29 Breast reconstruction
- 31 Lymphoedema
- 32 Breast prostheses
- 33 Radiotherapy
- 36 Chemotherapy
- 39 Biological therapies
- 41 Hormone therapy
- 44 Clinical trials
- 45 How can I cope with fatigue?
- 46 Managing menopausal symptoms
- 48 Coping with hair loss
- 49 Coping with changes in your appearance
- 50 Bone health and osteoporosis
- 51 Will treatment affect my sex life?
- 53 Will treatment affect my fertility?
- 54 What follow-up will I need?
- 55 Cancer and complementary therapies

Coping and emotions

- 57 How can I cope with my feelings?
- 62 How can my family and friends help?
- 62 Advice for carers
- 64 Talking to children and teenagers
- 65 Life after cancer

Support resources

- 67 Coping with the financial impact of cancer
- 69 Irish Cancer Society services
- 71 Local cancer support services
- 72 Helpful books
- 73 Questions to ask your doctor
- 74 What does that word mean?

Introduction

This booklet has been written to help you to learn more about breast cancer. The booklet is divided into 4 parts:

- **About breast cancer** gives an introduction to breast cancer.
- **Treatment and side-effects** discusses the different treatments used for breast cancer and possible side-effects.
- **Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having cancer.
- **Support resources** gives information on where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

>>> Reading this booklet

Remember you do not need to know everything about breast cancer straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 69 for more about Daffodil Centres. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



Cancer Nurseline Freephone 1800 200 700

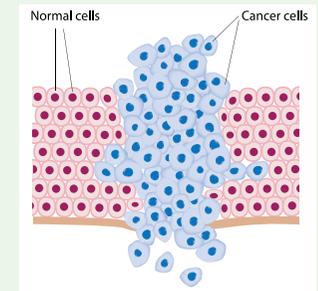
About breast cancer

>>> What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast.

All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

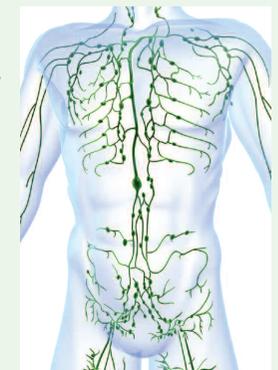
Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body, where they can form a secondary tumour. This is also called metastasis.



Cancer cells

What is the lymphatic system?

The lymphatic system protects us from infection and disease. It is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system

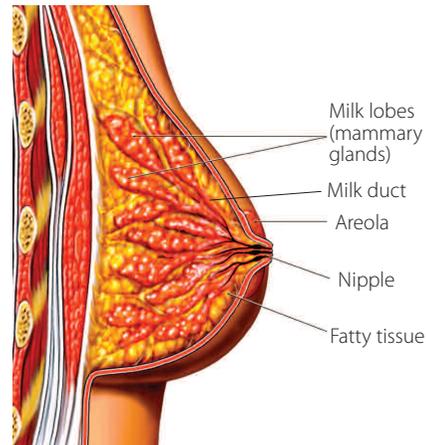


To sum up

- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by your bloodstream or lymph to form a tumour somewhere else. This is called a metastasis or secondary tumour.

What are the breasts?

Your breasts are made up of different types of tissue including fat, connective tissue and gland tissue. The gland tissue is divided into milk lobes and milk ducts. During and after pregnancy, milk is made and stored by the lobes and carried to the nipple by the ducts. Your breasts are rarely the same size as each other. They may feel different at different times of the menstrual cycle, sometimes becoming lumpy just before your period. Under your skin, a 'tail' of breast tissue extends into your armpit (axilla). The armpits also contain a collection of lymph nodes (glands) that make up part of the lymphatic system (see page 5).



The breast

What is breast cancer?

Breast cancer is when the cells in your breast tissue grow in an abnormal way.

What are the types of breast cancer?

There are many different types of breast cancer. To find out which type you have, the laboratory doctor called a pathologist will look at your cells under the microscope. Breast cancer may be described as:

- Non-invasive breast cancer
- Invasive breast cancer

Non-invasive breast cancer

The main non-invasive breast cancer is ductal carcinoma in situ (DCIS). DCIS is the earliest stage of breast cancer. It may also be described as pre-cancerous or intraductal. With DCIS the cancer cells have formed inside the milk ducts but have not spread outside them. Most people have no symptoms at all and are usually diagnosed from a mammogram (breast X-ray). If DCIS is not treated it can sometimes become an invasive cancer. There is more information on DCIS on our website, www.cancer.ie.

Invasive breast cancer

Invasive breast cancer means the cancer cells have moved beyond the lining of the milk ducts and invaded the surrounding breast tissue. Invasive breast cancer is capable of spreading outside the breast to the lymph nodes and to other parts of your body. The main types are:

Invasive ductal carcinoma: This is the most common type of breast cancer. It starts in the milk ducts of your breast, but then invades the surrounding tissue of your breast. It accounts for about 8 out of 10 of all invasive breast cancers.

>>> Invasive ductal carcinoma is the most common type of breast cancer.

Invasive lobular breast cancer: This type starts in cells that make up the lobes at the end of the milk ducts. Invasive lobular breast cancer is not common. It affects about 1 in 10 of all women with breast cancer. This cancer has a slightly higher chance of being in more than one area of the breast and of affecting both breasts.

Inflammatory breast cancer: In this type of breast cancer the overlying skin of your breast has a reddened appearance, like that seen with some breast infections. The reddened appearance is caused by breast cancer cells blocking tiny channels in the breast tissue called lymph channels. This is a rare type of breast cancer, accounting for only 1 or 2 in every 100 breast cancers. This type of breast cancer requires treatment by chemotherapy before surgery.

Paget's disease of the breast: This is an uncommon form of breast cancer. It starts in the breast ducts and spreads to the skin of the nipple and the areola, which is the dark circle around your nipple. It occurs in about 1 in 100 women with breast cancer. Men can also get Paget's disease but this is very rare.

Rarer types of breast cancer can include medullary, mucinous, tubular and malignant phyllodes tumour. If you are diagnosed with a rarer type of breast cancer, your doctor will give you further information. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more details.

Advanced or recurrent breast cancer

Advanced cancer is when cancer has spread to another part of your body. Cancer that has spread to another part of your body can also be called metastatic or secondary cancer. Your cancer may be advanced when it is first diagnosed. Or it may have come back sometime after you were first treated. This is called recurrence.

This booklet does not deal with breast cancer that has spread or come back. If you need more information, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of the booklet, *Understanding Secondary Breast Cancer*, or see our website www.cancer.ie

Hormone and protein receptors

Breast cancer can also be described by the type of receptors or proteins on the surface of the cancer cells.

Hormone-receptors: In breast cancer, some receptors mean that hormones will encourage the cancer cells to grow. For example, the hormones oestrogen or progesterone.

HER2 protein receptors: Your breast cancer cells may have too many HER2 protein receptors. HER2 can encourage breast cancer to grow.

Using receptor information to describe breast cancer:

- **Hormone receptor-positive breast cancer:** This means your breast cancer cells have extra oestrogen or progesterone receptors.
- **Hormone receptor-negative breast cancer:** This means your breast cancer cells don't have any extra oestrogen or progesterone receptors
- **HER2 positive breast cancer:** This means the breast cancer cells have large numbers of the HER2 protein on their surface, which can help the cancer cells to grow.
- **HER2 negative breast cancer:** This means the breast cancer cells don't have extra HER2 protein on their surface.
- **Triple negative breast cancer:** This means the breast cancer cells don't have receptors (proteins) on the surface of the cancer cells for the hormones, oestrogen, progesterone or HER2. It occurs in about 1 in 5 women with breast cancer and often in younger women.
- **Triple-positive breast cancer:** This means the breast cancer cells have extra receptors for oestrogen and progesterone and have too much HER2.

Knowing about the receptors or proteins on the surface of your breast cancer cells can help the doctor decide which hormone therapies or biological therapies will be most effective for you.

How common is breast cancer?

Breast cancer is the second most common cancer in women in Ireland. Each year it affects about 3,000 women and 20 men in this country.

What increases my risk of breast cancer?

The exact cause of breast cancer is unknown. But there are certain risk factors that can affect your chance of getting the disease.

Having a risk factor doesn't mean you will definitely get cancer. And sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of breast cancer are:

- **Gender:** Breast cancer is 100 times more common in women than in men.
- **Age:** Breast cancer is rare in women under 30 and occurs most often over the age of 50.
- **Previous breast disease:** Your risk is increased if you were previously diagnosed with breast cancer, atypical ductal hyperplasia (ADH) or lobular neoplasia.
- **Previous radiotherapy:** If you were treated with radiation to your chest area in the past, your risk of breast cancer is higher. For example, having had mantle radiotherapy for Hodgkin lymphoma.
- **Hormones:** Starting your periods at an early age, having your first child at an older age, a late menopause, taking the combined form of HRT for over 5 years, and the contraceptive pill can all increase your risk of breast cancer.
- **Lifestyle:** There are other factors that might increase your risk of getting breast cancer. These include: being physically inactive or overweight, smoking, drinking alcohol, and a diet high in fat and low in fibre and fresh fruit and vegetables.
- **Family history:** Your risk is higher if there is breast cancer in several close members of your family, or other cancers like ovarian or bowel cancer as well as breast cancer; or breast cancer in a close relative under the age of 40, especially if the cancer was in both breasts.

Hereditary breast cancer



A very small number of breast cancers are caused by an inherited faulty gene, inherited from either of your parents. This is called hereditary or familial breast cancer.

Two of the most common genes that can cause breast cancer are the BRCA1 and BRCA2 genes. If you have the BRCA1 or BRCA2 gene, other members of your family may have inherited this faulty gene. If they have the BRCA1 or BRCA2 gene, they are more at risk of developing breast or ovarian cancer. Your doctor may recommend that other members of your family have a genetic test to see if they too have the BRCA gene. Having the gene doesn't mean that a person will definitely get breast or ovarian cancer, it just means their risk is greater.

For more detailed information on hereditary breast cancer and genetic testing, see our website www.cancer.ie. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse.



To sum up

- Breast cancer happens when the cells in your breasts grow in an abnormal way.
- Breast cancer can be pre-invasive (DCIS) or invasive.
- Breast cancer can be described by the receptors or proteins on the surface of the breast cancer cells.
- The cause of breast cancer is unknown. But your gender, age, history of previous breast disease, previous radiotherapy, hormones, family history of cancer and your lifestyle can affect your chances of getting the disease.

Email cancernurseline@irishcancer.ie

Being diagnosed with breast cancer

Hearing that you have breast cancer can be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Scared** about the future

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:

- Ask to speak to the breast care nurse, cancer liaison nurse or medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Telling people about your diagnosis



It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?

After you have been diagnosed with breast cancer, you may have more tests to find out about your cancer and your general health.

Tests you may have include:

- **Lymph node ultrasound scan:** This is a scan that uses sound waves to look at the lymph nodes in the area of your armpit (axilla), to see if they look abnormal. The scan is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. If the lymph nodes look abnormal, a biopsy (tissue sample) will be taken to see if the cancer has travelled to the lymph nodes. It's important to know this, as it will influence what type of treatment you will need.
- **Blood tests:** Blood tests can check your general health, for example, to make sure you are fit for surgery. These blood tests can also give information about your liver and bones. You may need to have an X-ray or scans if your blood tests results show any abnormal changes.

- **X-rays:** X-rays use high-energy rays to take pictures of the inside of your body. They can check for bone and other joint problems.

X-rays can also show changes in tissues and organs, such as the breasts (mammogram) and lungs (chest X-ray). You may have a chest X-ray to check you are fit for surgery. You may need a spine X-ray if you are having back pain.



- **MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. No radiation is used in an MRI. During the test you will lie inside a tunnel-like



machine. The tunnel is open at either end, but some people get anxious or worried that they will feel claustrophobic during the test. If you are anxious, talk to your breast care nurse the day before. They may be able to give you medication to relax you. It can also be noisy, but you will be given earplugs to wear. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or bone pin, you may not be suitable for the test. Usually you can go home after the scan.

Other tests

- **CT scan (CAT scan):** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before the test, let your breast care nurse know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.
- **Bone scan:** For this test a tiny amount of a mildly radioactive substance is injected into a vein, usually your arm. A scan is then taken of all the bones in your body. Because abnormal bone absorbs more of the radioactive substance than normal bone, the abnormal bone shows up as highlighted areas. After the injection you will have to wait about 3 hours before the scan can be taken. You may want to bring a book or magazine with you, or a friend to keep you company. The level of radioactivity is very low and disappears within a few hours. But do avoid babies, young children, and pregnant women until the day after the test. The test is not recommended for pregnant women.
- **Liver ultrasound scan:** This scan uses sound waves to check the health of your liver. It is a quick, painless test, usually done in the hospital X-ray department. You will be asked to lie on a couch and a gel will be spread on your tummy (abdomen). A small device like a microphone will then be passed over the area. The sound waves are changed into a picture using a computer so your doctor can see any changes to your liver. You may need to fast (not eat) for a few hours beforehand. Check with your doctor or breast care nurse.
- **PET scan:** PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where

the cancer cells are found. An hour after the injection, you will lie on a table, which moves through a scanning ring. The scan pictures can show if there are cancer cells in other parts of your body. Your doctor or nurse in hospital will tell you how to prepare for the scan. For example, avoiding strenuous physical activity for 24 hours and no food or drink except water for around 6 hours before the test. Make sure you understand and follow any instructions, so that the test can be done as planned.

Waiting for test results

It usually takes about a week for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



Staging and grading breast cancer

The tests you have after diagnosis help the doctor to give your cancer a stage and a grade. Staging means finding out the size of the cancer and if it has spread to other parts of your body. Grading describes how quickly the cancer is growing in your breast. Knowing the stage and grade of your cancer is very important, as it helps your doctor to decide the best treatment for you.

How is breast cancer staged?

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor often uses this information to give your cancer a number stage – from 0 to 4. Some stages are further divided into stage A and B.

In general, the lower the number, the less the cancer has spread. A higher number, such as stage 4, means a more serious cancer.

What are the stages of breast cancer?

Stage 0: Non-invasive breast cancer, e.g. DCIS

Stage 1: The cancer is found only in your breast

Stage 2: The cancer is found your breast and nearby lymph nodes

Stage 3: The cancer has spread to more lymph nodes

Stage 4: The cancer has spread to other organs in your body.

How is breast cancer graded?

Grading describes how the breast cancer cells look under the microscope. The cells can be graded as 1, 2 or 3, depending on how different they are to normal breast cells and how quickly they are growing. In general, a lower grade (1) means a slower-growing cancer, while a higher grade (2 or 3) means a faster-growing cancer.

Staging and grading can be hard to understand, so ask your doctor and nurse for more information if you need it.

>>> Staging and grading allow your doctor to decide the best treatment for you.



To sum up

- You may have tests like a lymph node ultrasound scan, MRI scan or PET/CT scan to stage your cancer.
- Staging cancer means finding out its size and if it has spread outside the breast.
- Grading describes how quickly the cancer is growing in your breast.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It is not always easy for doctors to answer a question about life expectancy, as the answer is based on a 'typical' experience. In reality, experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment and side-effects

How is breast cancer treated?

The aim of treatment is to stop any spread of the cancer and, if possible, to remove all the cancer from your body. In deciding on the most suitable treatment, your doctor will consider:

- The size of the tumour
- The type of breast cancer
- Your age and general health
- Whether or not you have been through the menopause
- If the tumour has spread to the lymph nodes or other parts of your body
- If your cancer cells express hormone-receptors or HER2 protein receptors (see page 9)

What types of treatment are used?

The main treatments for breast cancer are:

- Surgery
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Biological therapies

The treatments may be used alone or in combination with each other, and not necessarily in this order.

Specialist cancer centres

Breast cancer is treated in specialist breast cancer centres in Ireland. The staff at these centres have great expertise in managing patients with breast cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Deciding on treatment

Multidisciplinary team: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, surgeon, medical oncologist, radiation oncologist, radiologist, pathologist and breast care nurse.

The team will meet to discuss your test results and your suggested treatment plan.

Treatment options: Your doctor and nurse will explain your treatment options to you. Ask as many questions as you like, no matter how small or trivial you think they are. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again.

Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Who will be involved in my care?

Usually a team of health professionals will be involved in your treatment and care.

| | |
|---|--|
| Breast surgeon | A doctor who specialises in breast surgery and who can remove the tumour from your breast. They may also perform breast reconstruction surgery. |
| Radiologist | A doctor who specialises in interpreting X-rays such as mammograms and ultrasound scans, as well as CT, MRI and PET scans. The breast radiologist is also the doctor who usually takes the biopsy samples and places markers in your breast before surgery, if needed. |
| Medical oncologist | A doctor who specialises in treating cancer patients using chemotherapy and other drugs. |
| Radiation oncologist | A doctor who specialises in treating cancer patients using radiotherapy. |
| Radiation therapist | A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment. |
| Breast care nurse / oncology liaison nurse / clinical nurse specialist | A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment. |
| Pathologist | A specialist who examines tissue samples (biopsies) under a microscope to diagnose cancer and other diseases. |

| | |
|--|---|
| Plastic surgeon | A surgeon who specialises in repairing and rebuilding different parts of your body. He or she can do different types of breast reconstruction. |
| Cancer genetics consultant/specialist | A specialist in genetic testing. He or she can advise you about how your genes may affect your treatment. |
| Medical social worker | A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home. |
| GP (family doctor) | You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope. |
| Physiotherapist | A therapist who treats injury or illness with exercises and other physical treatments related to the illness. |
| Dietitian | An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms. |
| Psycho-oncology team | These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses. |
| Psychologist | A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions. |
| Counsellor | A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. |
| Community health services | This includes family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services. |

Individual treatment

You may notice that other people with breast cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers waiting for a few weeks for scans or treatment does not usually affect how well the treatment works. It's important for your doctors to get all the information about the type and stage of your cancer before starting your treatment.

If you are worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



Surgery

Most women who are treated for breast cancer have some type of surgery.

Your surgeon will discuss with you the most suitable type of surgery.

There are two main types of surgery:

- Breast-conserving surgery – Part of the breast is removed
- Mastectomy – The whole breast is removed

The type of surgery you need usually depends on the size of the cancer relative to your breast size, where it is in your breast, and if there are any more areas of disease in your breast.

Breast-conserving surgery

In this type of surgery, only part of your breast is removed. You will need radiotherapy treatment afterwards.

There are different types of breast-conserving surgery. The type of surgery you have depends on how much of your breast tissue needs to be removed and where in your breast the cancer is found. All types of breast-conserving surgery will leave some type of scar.

Types of breast-conserving surgery

Lumpectomy / Wide local excision: These surgeries remove only the breast lump and some normal tissue around it.

Segmental excision or quadrantectomy: These kinds of surgery remove more of the breast tissue than a lumpectomy or wide local excision.

After surgery, a pathologist examines the tissue removed to see if any cancer cells remain. If they find cancer cells at the edges of the piece of tissue removed, this is called a positive margin. When no cancer cells are found at the edges of the tissue, this is called a negative or clear margin.

If you have a positive margin, it may mean that some cancer cells remain after surgery. Your surgeon may need to go back and remove more tissue. This operation is called a re-excision of margins. If your surgeon cannot remove enough breast tissue to get clear margins, you may need to have a mastectomy.

Mastectomy – removing one breast: For some women, the best treatment is to remove the whole breast. This is called a mastectomy. After a mastectomy, you will be offered a prosthesis (breast form) to wear. (see page 32). Breast reconstruction is surgery that restores the appearance of your breast. It may be suitable for some women, either immediately at the time of mastectomy or later on (see page 29).

Bilateral mastectomy – removing both breasts: Some women may need to have both breasts removed. This is called a bilateral mastectomy or double mastectomy. Reconstruction may be possible for women who have both breasts removed. Your surgeon will discuss this with you. Having both breasts removed can be very traumatic. It may help to talk to a woman who has had bilateral surgery. Our cancer nurses can help you if you would like to talk to a trained volunteer who has been through a similar experience. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and ask about Survivor Support.

Choice of surgery

You may be given a choice between breast-conserving surgery and mastectomy. One advantage of breast-conserving surgery is that you keep most of your breast, which will have a scar. A downside is the need for radiotherapy after breast-conserving surgery. But some women who have a mastectomy may still need radiotherapy.

If you are treated with either of these two methods, it will not affect your survival rate. You may also have other reasons for preferring one type of surgery. Conserving the breast is not an option for all women with breast cancer. Discuss your own situation with your surgeon.

Sentinel lymph node biopsy

If breast cancer spreads, the first place it spreads to is the lymph nodes in your armpit (see page 5). It's important to know if the cancer has spread, as it will affect the treatment you will need. If scans and other tests show no signs of cancer in your lymph nodes, you may have a test called a sentinel lymph node biopsy.

The sentinel node is the first lymph node (or group of nodes) to drain fluid from the breast, so it is the most likely to contain cancer cells if the cancer has spread. It is normally in your armpit (axilla) on the same side as the breast cancer. Removing and examining the sentinel node and perhaps one or two other nodes can show if the cancer has spread, without having to remove all the lymph nodes.

A sentinel lymph node biopsy means you spend less time in hospital, have less discomfort and reduces the risk of lymphoedema (swelling) in your arm, compared to a complete removal of all the lymph nodes in the area (see page 27). For more about lymphoedema, see page 31. Sometimes this test is done a few days before the main breast surgery.

During the test: The test involves injecting a small amount of radioactive material into your breast, usually on the morning of the operation or the evening before. This part of the test is carried out in the X-ray department. The radioactive dye follows the path that the cancer cells would take from the breast through the lymphatic system. A picture may be taken at time intervals after the injection. This may help your surgeon to identify the sentinel node. The sentinel node is usually removed during the same operation as your breast surgery. Sometimes it's done before surgery to get more information to guide your cancer treatment. In both cases you will have a general anaesthetic. During the surgery the surgeon uses a probe to see the nodes in your armpit that have taken up the radioactive dye. Sometimes a blue dye is also injected into your breast at the time of surgery to help locate the sentinel node. The lymph nodes that have taken up the radioactive dye, or are stained with the blue dye, are removed. Usually one to three nodes are removed.

After the test: The nodes removed are sent to the pathologist, who looks at them closely under the microscope to see if the sentinel node contains cancer.

It may take up to 10 days or longer for the pathologist to examine the sentinel nodes and give the final results. Sometimes the pathologist will examine the nodes and give results during your breast surgery, if the surgeon needs the results immediately.

If the sentinel lymph node is clear of tumour cells, it means that the other lymph nodes should also be clear. But if the sentinel lymph node is not clear of tumour cells, then further surgery to the lymph nodes may be needed. Your doctor will discuss this with you.

Lymph node removal

If the doctors have found cancer in your lymph nodes before your surgery, or if the lymph nodes from your armpit are tested and show cancer cells, some more nodes will be removed. In some cases, most of the lymph nodes in your armpit will need to be removed. This is called an axillary clearance. For most women this operation can be done without causing serious difficulty with shoulder movement, or arm swelling. After this operation a drain will be put in to take away lymph and other fluids for a few days. The drain is removed when there is a decreased amount of fluid flowing out. You will also need to do special arm exercises as shown by the hospital physiotherapist. There is a small risk of swelling in your arm (lymphoedema). This can happen any time after the operation. See page 31 for more about lymphoedema. The area under your arm will feel numb or sore for a while and you may experience some tingling or pins and needles. You may also experience some discomfort, but you will receive regular painkillers to help with this.

After your breast surgery

You will be encouraged to get out of bed and start moving about as soon as possible after your operation. You may have one or two drainage tubes (drains) in your wound. These will usually be removed a few days after the operation by the nurses on the ward. You can get up and move around carefully with these drains in place.

The length of your stay in hospital will depend on the type of surgery you have had. After breast-conserving surgery, your stay will probably be quite short. After a mastectomy your stay could be several days or longer.

After an axillary clearance, your stay is usually longer. It can depend on the amount of fluid in your drains. After a sentinel lymph node biopsy, your hospital stay will be shorter.

Often you can go home with drains in place, if you and your surgical team are happy that you can empty and manage them yourself. They will be removed later by your breastcare nurse or your public health nurse.

Side-effects of surgery

Pain: After your operation you may experience some pain or discomfort, which can continue for several weeks. There are various types of very effective painkillers available. If you do have pain, at home or in hospital, it is important to tell your doctor or nurse so that effective painkillers can be prescribed.

Stiffness: A physiotherapist will advise you on the special arm exercises you need to do to prevent your arm and shoulder joint from getting stiff. There are usually special exercises to follow before and after the drains come out. If you have any difficulties with these exercises at home, you can usually contact the physiotherapist or breast care nurse.

Sensation in wound: You may experience different sensations in your breast wound or scar. It may feel numb or be extra sensitive to touch.

Fluid under wound: After the drains have been removed, fluid may collect under the wound. This is called a seroma and can feel like a lump. Don't worry if this happens. Tell your doctor or breast care nurse, who can drain the fluid with a needle, if necessary. This normally only takes a few minutes and is not usually uncomfortable. A build-up of fluid or seroma does not always need to be drained. Sometimes the fluid is gradually reabsorbed by the body.

Leaving hospital

Before you leave hospital you will be given an appointment for a follow-up visit at the outpatient clinic. You can contact your breast care nurse if you have any worries or problems before the date of your appointment. For more about follow-up see page 54.

When you get home, take things easy for a while. You may feel physically and emotionally exhausted. Try to have long rest periods and eat a well-balanced diet. You will probably be advised not to lift or carry anything heavy or drive for a few weeks.

Breast reconstruction

It is often possible for women who have had a mastectomy to have breast reconstruction. The aim of reconstruction is to try to restore the breast shape, matching the remaining natural breast as closely as possible. This can either be done by creating a breast 'form' with an implant that is placed beneath the skin and muscle that covers your chest, or by using skin, fat and muscle from another part of your body. A combination of these techniques is used for some women. Sometimes this can be done at the same time as the mastectomy, but often it is done some months or even years after the original operation. You may have a number of choices if you decide to have reconstructive surgery, though one type of operation may be more suitable than another.

Why have a breast reconstruction?

Some women find it harder than others to accept the idea of losing one or both of their breasts. It is natural to feel distressed, and every woman has the right to do something about their loss. Some women may feel guilty for thinking about reconstruction and think that it might seem vain. This is not so – reconstruction can be an important part of helping you to recover emotionally and to feel better.

If you would like to consider breast reconstruction, discuss it with your surgeon or breast care nurse before surgery. He or she can tell you about the different methods available or refer you to a plastic surgeon. For more information see our website, www.cancer.ie

You can read our booklet, *Understanding Breast Reconstruction*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also read or download the booklet on our website.



Email cancernurseline@irishcancer.ie

Breast surgery and your emotions

Whether you lose part of your breast or all of it, any change to your body image can be very traumatic.

Recovering emotionally from breast surgery can take some time. Try not to worry too much if you feel you are not coping as well as someone else you know who has also had breast surgery. If you are finding it difficult or feeling alone, remember that there are people who can help you. Tell your family and friends how you feel so they can support you. You can also talk to your breast care nurse or call our Cancer Nurseline on Freephone 1800 200 700 to talk to a cancer nurse in confidence. You can also talk to a nurse in a Daffodil Centre. See page 57 for more about feelings and emotions.



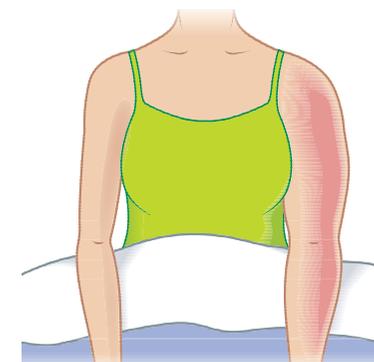
To sum up

- Surgery is one of the main treatments for breast cancer.
- You may have part of your breast removed (breast-conserving surgery) or you may need to have the whole breast removed (mastectomy).
- If you have a mastectomy, you may have breast reconstruction surgery, either at the time of the mastectomy or later on.



Lymphoedema

If your surgeon has removed some lymph nodes from under your arm, or if you have had radiotherapy to your lymph nodes, you may be at risk of a condition called lymphoedema. Lymphoedema is a swelling caused by a build-up of lymph fluid in the tissues of your arm on your operation side.



Lymphoedema can happen immediately after surgery or radiotherapy to your lymph nodes or it can develop later, sometimes many years after treatment.

If you notice swelling anywhere on your arm, hand or breast area, even if it comes and goes, you should tell your GP, oncologist or breast care nurse. Other signs to watch out for are:

- A feeling of tightness when wearing clothing, bracelets, watches, or rings.
- A full, heavy, achy or weak feeling in the arm.
- A tight feeling in the skin.
- Dry, flaky, rough or scaly skin, or changes to your skin colour.
- Trouble moving your arm.

»»» Tell your doctor straight away if you notice any swelling. Lymphoedema is much easier to manage if you get treatment early.

Your doctor can refer you to a lymphoedema therapist who can recommend treatments to help keep it under control.

There is more information on lymphoedema and tips on managing the condition on our website, www.cancer.ie. You can also get information and advice from a cancer nurse by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre.

Breast prostheses

A breast prosthesis is an artificial breast form which fits into a bra cup to replace your natural breast after a mastectomy.



Prosthesis shapes

Prostheses come in a wide variety of different shapes, sizes and skin colours. They are made from materials that will move, feel and weigh like a normal breast. A breast prosthesis can help to improve your balance and posture after breast surgery. You should be able to find a prosthesis to suit your particular needs. The most common type of prosthesis rests against your chest wall and is held in place by your bra, but there are a number of different types to choose from.

After surgery, you will not be able to wear anything that puts pressure on your scar and the surrounding area for 6–8 weeks. During this time you can wear a lightweight temporary prosthesis. Often this will be fitted before you leave the hospital. When the breast area has healed, you can be fitted with a permanent breast prosthesis. This is made from silicone gel moulded to form the natural shape of your breast.

Your breast care nurse or a trained mastectomy fitter will do the fitting for you. An appointment may be made for you before you leave the hospital. For more information or to find a fitter near you, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also find more detailed information about breast prostheses on our website, www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy may be given at different times and for different reasons. For example:

- After surgery or chemotherapy to reduce the risk of the cancer coming back left. This is called adjuvant treatment.
- To control and relieve symptoms of advanced cancer. This is called palliative radiotherapy.

Radiotherapy can be given in two ways: externally and internally. With external beam radiotherapy, the radiation comes from machines which aim rays directly at your tumour or the tumour site.

In the case of internal radiotherapy, the radiation source is placed inside your body in special applicators on or near your tumour. It is possible to have both external and internal radiotherapy.

Planning your treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken, but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. These centres need highly trained staff and space for the large equipment involved. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

How much radiotherapy do I need?

The course of external beam radiation is usually daily for 3-6 weeks, or between 1 and 10 doses for palliative treatment.

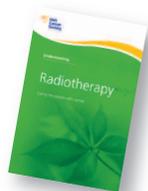
External radiotherapy does not make you radioactive. It is safe for you to mix with family and friends, including children and pregnant women.

Internal radiotherapy

With internal treatment, the radiation source is placed inside your body on or near your tumour. The radiation source is sealed and referred to as an implant. This treatment is also known as brachytherapy. The type of brachytherapy for breast cancer is also called interstitial (in-ter-stit-ee-al) radiotherapy.

For some internal radiotherapy you may have to stay in hospital for a few days.

For more information on radiotherapy or a copy of our booklet *Understanding Radiotherapy*, call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



Side-effects of treatment

Radiotherapy is given directly to the site of the cancer. Therefore, most of the side-effects that occur are related to the part of your body being treated. When the breast is being treated, the most common side-effects are:

- Skin changes
- Tiredness (fatigue)
- Indigestion

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks.

Late side-effects of radiotherapy to the breast

Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent. Late side-effects include:

- Changes to the colour or feel of the breast. For example, blood vessels appearing, or hardening of the breast tissue
- Muscle tightness and loss of movement in the chest or shoulder area
- Lymphoedema (see page 31)
- Breast swelling and pain can happen for up to a year after radiotherapy.

If you feel unwell or have any other side-effects or symptoms, during or at any time after treatment, tell your doctor, nurse or radiation therapist.

For more information on the side-effects of radiotherapy or a copy of the booklet *Understanding Radiotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Radiotherapy uses high-energy X-rays to kill cancer cells.
- A lot of preparation is needed before treatment is given.
- The main short-term side effects of radiotherapy to the chest area are skin changes, tiredness (fatigue) and indigestion.
- Late side-effects include changes to the colour or feel of the breast, loss of movement in the chest or shoulder area, lymphoedema and breast swelling or discomfort.

Email cancernurseline@irishcancer.ie

Chemotherapy

Chemotherapy is a drug treatment used to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy drugs may be given at different times and for different reasons:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- As a treatment on its own to treat cancer that has spread or come back. This is called primary chemotherapy.

Oncotype DX® test

The Oncotype DX® test looks at a sample of your breast cancer tissue under the microscope. The doctor will remove a sample (biopsy) during surgery. The Oncotype DX® test examines 21 genes found in your breast cancer tissue to give you a recurrence score. This score can help to predict how likely it is that your cancer will return in the future. It also helps to show how effective chemotherapy will be for you.

The Oncotype DX® test can be used if your breast cancer is early stage, lymph node negative (no cancer cells in your lymph nodes), oestrogen-receptor-positive (ER+) or HER2 negative (see page 9).

For more information on this test, and information on understanding recurrence scores, see our website www.cancer.ie



How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period gives your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat breast cancer. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (throwing up). There are treatments available that work well to prevent nausea and vomiting.
- **Infection:** Your white blood cells that help to fight infection can be reduced by chemotherapy. This may make you more likely to get infections. Your white blood cell count will be checked regularly during chemotherapy. You will be asked to watch out for signs of infection. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.
- **Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Hair loss (alopecia):** Most chemotherapy drugs for breast cancer cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have hair loss. For more information on hair loss, see page 48.

- **Bleeding and bruising:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help to make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Mouth and throat problems:** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are mouthwashes and medications to help, which your doctor can prescribe for you.
- **Menopausal symptoms:** Chemotherapy can affect your ovaries, so you may experience the symptoms of the menopause, like hot flushes. Sometimes chemotherapy brings on an early menopause. For more about managing menopausal symptoms see page 46.
- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).
- **Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 45.
- **Skin and nail changes:** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.
- **Peripheral neuropathy:** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.
- **Changes in kidney function:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.
- **Effects on fertility:** Chemotherapy can affect your fertility in the short term. For example, you may not have periods for up to a year after treatment. You should still take contraceptive precautions even if your periods have stopped while you are having chemotherapy. Chemotherapy can also cause permanent changes that mean that you will not be able to have a child in the future. For more about breast cancer treatment and fertility, see page 53.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. He or she will tell you what to do.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Chemotherapy is a treatment using drugs to control or cure cancer.
- Chemotherapy can be given in tablet form, directly into a vein as an injection, or through a drip.
- The side-effects vary from person to person depending on the drugs used. Most side-effects can be well controlled with medication.
- Breast cancer chemotherapy drugs usually cause hair loss.

Biological therapies

Biological therapies work with your body. They can help fight cancer, stop it spreading or control side-effects from other cancer treatments.

With breast cancer, biological therapies are used for women who have HER2 receptors on the surface of their breast cancer cells. The biological therapy blocks the receptors on the cells, so that HER2 proteins can't attach to the cells and help them to grow. It also helps the immune system to target and kill the cancer cells.

Different treatments are available for advanced (secondary) breast cancer. See our booklet *Understanding secondary breast cancer* for more information.

Different types of biological therapies work in different ways. For example:

- Cancer growth inhibitors block the chemical signals that trigger cancer cells to divide and grow.
- Monoclonal antibodies trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.

- Angiogenesis inhibitors interfere with the blood supply to the cancer cells.
- Immunotherapy boosts your body's immune system to fight cancer.

Some treatments fit into more than one of these groups.

The type of biological therapy most commonly used for breast cancer are monoclonal antibodies. An example is trastuzumab (Herceptin®). This drug is only used for HER2 positive breast cancer.

Usually biological therapy drugs are given into a vein through a drip or as an injection. Other drugs may be given as a tablet.

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 44). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.



Side-effects

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy.

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include flu-like symptoms such as a headache, high temperature (fever) and chills, or feeling sick. You may also get diarrhoea.

Your doctor and nurse will explain your treatment in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if any symptoms are troubling you.

For more information on biological therapies and their side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Biological therapies work with your body to fight cancer.
- The drugs are usually given into a vein through a drip or with an injection.
- With breast cancer, biological therapies are used for women who have HER2 positive cancer.
- Some side-effects include small flu-like symptoms and diarrhoea.

Hormone therapy

Some women have breast cancers that are sensitive to the hormones oestrogen or progesterone. This means that your cancer cells have extra receptors on their surface that attach to the female hormone oestrogen. This is called oestrogen-receptor positive cancer (see page 9). The oestrogen helps the cancer cells to grow faster. Oestrogen-receptor positive cancers are common:

- Just over half of women who get cancer before the menopause have oestrogen-receptor positive cancer.
- About 3 in 4 women who get cancer after the menopause have oestrogen-receptor positive cancer.

Hormone therapy works by blocking the effects of oestrogen on breast cancer cells.

Hormone therapy may be given:

- Before breast surgery, to try to make the tumour smaller and easier to remove. This is called neoadjuvant treatment.
- After breast surgery to help prevent cancer spreading or coming back. This is called adjuvant treatment.
- Instead of surgery, where surgery is not possible

Is hormone therapy suitable for me?

If your breast cancer is not sensitive to hormones, hormone therapy will not be of benefit. You may be offered chemotherapy, or no further treatment may be needed.

To see if you will benefit from hormone therapy, a tissue sample of your cancer cells will be tested for hormone receptors. A small number of breast cancers are sensitive to the hormone progesterone only. In this case, your doctor will discuss the possible benefits and risks of hormone treatment with you.

Types of hormone therapy

Hormone therapies are designed to stop oestrogen from helping the cancer to grow. The drugs work in different ways:

By blocking the receptors on the cancer cells. This means oestrogen cannot attach to the cells. An example of a hormone therapy drug that works in this way is tamoxifen.

By stopping your ovaries from making oestrogen. Hormone therapy drugs that work in this way are called luteinising hormone-releasing hormone (LHRH) analogues. They change the levels of hormones released in your brain that control how your ovaries work. The effects of these drugs are usually reversible once the drug is stopped. It usually depends on your age. An example of an LHRH analogue is goserelin (Zoladex®).

By blocking the production of oestrogen in your body fat. Drugs called aromatase inhibitors stop the enzyme aromatase from changing the hormone androgen into oestrogen. These drugs are for women after the menopause (postmenopausal), who don't produce oestrogen in their ovaries any more. Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®).

Hormone therapy is often given as tablets, or you may have an injection under your skin. It depends on the type of drug used.

Other ways to reduce oestrogen levels in your body

Chemotherapy: Chemotherapy may stop your ovaries from working normally. This can also reduce oestrogen levels. This may be reversible, depending on your age.

Surgery: This is where your ovaries are removed so no oestrogen will be produced. This is a non-reversible procedure.

Ovarian ablation or suppression

Ovarian ablation means removing your ovaries.

Ovarian suppression means stopping your ovaries from working.

Side-effects of hormone therapy

Hormone therapy may cause short- or long-term side-effects. As with all drugs, side-effects can vary. Side-effects include:

- **Menopausal symptoms:** Hormone therapy can reduce the amount of oestrogen in your blood. This can cause the symptoms of the menopause, like hot flushes. For more about managing menopausal symptoms see page 46.
- **Osteoporosis:** If you have not yet gone through the menopause, you may be at risk of osteoporosis (brittle bones). This is due to less oestrogen in your body caused by hormone therapy. Discuss with your doctor or nurse how it can be prevented. For more information see page 50.
- **Blood clotting:** Some treatments slightly increase the risk of blood clotting. Tell your doctor if you have any vaginal bleeding, chest pain, swelling, or tenderness in your legs or arms.
- **Thickened womb:** Some drugs can cause the lining of your womb (uterus) to become thickened or put you at small risk of developing cancer of the womb. Tell your doctor if you have any vaginal bleeding while you are having treatment.
- **Bone loss and pain:** Some drugs may increase bone loss and cause pains and aches in your muscle or bone joints. If your treatment has this effect, you may have bone density scans before starting treatment and regularly while on this treatment. You should also stop smoking, take regular exercise and have foods containing calcium in your diet. Ask your doctor about taking calcium supplements. Drugs may be prescribed if there is serious bone loss (osteopenia).



To sum up

- Hormone therapy works by blocking the effects of oestrogen on breast cancer cells so they cannot grow.
- Hormone therapy only works for breast cancers that are sensitive to hormones.
- Hormone therapy is often given as tablets, or you may have an injection under your skin.
- Side effects of hormone therapy include menopausal symptoms, osteoporosis (brittle bones), blood clotting and bone pain.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that you get a new trial drug instead of the standard treatment. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it's safe to use in a clinical trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.



How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. When you have cancer, fatigue can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Usually fatigue improves once treatment is over, but it can carry on for some people. It is important to tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.



Tips & Hints – fatigue

- Try to do some exercise – Ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.



Managing menopausal symptoms

The menopause happens when a woman's periods stop. This happens because the ovaries stop producing the hormones oestrogen and progesterone. The symptoms of the menopause like hot flushes and mood changes are caused by the change in your hormones.

Treatments that stop your ovaries producing oestrogen can cause menopausal symptoms. For example, chemotherapy, hormone therapy and ovarian ablation. Even if you have had the menopause, you are likely to experience menopausal symptoms while on hormone therapy treatment.

These treatments can also cause your periods to stop (menopause). A menopause caused by breast cancer treatment can be quite sudden and symptoms are often more intense than when the menopause occurs naturally. Often, the younger you are, the more severe the symptoms. The menopause can be temporary or permanent. Women who are closer to the age of natural menopause (late 40s to mid-50s) are more likely to find that their periods don't come back after treatment.

The main menopausal symptoms are:

- Hot flushes / night sweats
- Dry skin and dryness of your vagina
- Lower sex drive
- Mood changes
- General aches and pains
- Poor concentration
- Trouble sleeping (insomnia)

There's more information on how to manage menopausal symptoms on our website www.cancer.ie.

Menopause and younger women

Going through the menopause and perhaps facing infertility an early age can be isolating. You may feel that you cannot share your experiences with your friends, or that they won't understand what you are going through. Talk to your doctor or nurse about your feelings. Or call our cancer nurses on 1800 200 700 for confidential advice and support.



Tips & Hints – dealing with menopausal symptoms

Menopausal symptoms can have a big impact on your day-to-day life, especially when you are trying to deal with a cancer diagnosis.

Fortunately, there are lots of treatments to help with most menopausal symptoms, and ways to help you cope better. For example:

- Prescription medications like hormone replacement therapy (HRT). HRT is not recommended after a diagnosis of hormone-sensitive breast cancer
- Complementary therapies like acupuncture and aromatherapy
- Relaxation techniques like meditation and yoga
- Dietary or herbal supplements like evening primrose oil and ginseng. Some products may not be suitable if your breast cancer is sensitive to oestrogen, so check with your doctor if you are planning to use complementary therapies.
- Emotional support from counsellors and support groups

Coping with hot flushes

- Avoid warm areas and use an electric fan to lower your skin temperature.
- Try avoiding spicy foods, caffeine, alcohol, sugar and hot drinks.
- Avoid hot baths or showers, as they may trigger a hot flush.
- Wear cotton or special wicking-fabric clothing. Cotton absorbs moisture and wicking fabrics take moisture away from the body to keep you dry and comfortable.
- Have layers of clothing and bedding so that you can remove or add layers as your body temperature changes.
- Keep a cool gel pack under your pillow at night
- Use sprays or moist wipes to help lower your skin temperature.
- Drink cold drinks.
- Taking regular exercise and being a healthy weight may reduce symptoms
- Don't smoke.

Ask your doctor about medication that may help.

Coping with vaginal dryness

- Vaginal moisturisers can be used every few days to help with vaginal dryness.
- If you experience discomfort during sex, water-based lubricants may help.
- Ask your pharmacist, doctor or nurse about which products are suitable.
- Ask your doctor about oestrogen treatments, such as rings or tablets used inside your vagina. Oestrogen products may not be suitable for you if your cancer is hormone-receptor positive.

Coping with hair loss

The chemotherapy drugs used to treat breast cancer usually cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it.

Your hair will start to grow back once your treatment has ended, usually within a few weeks. You should have a full head of hair within 6 months.

How will I feel if I lose my hair?

It can be really upsetting to lose your hair, especially when you are trying to deal with your cancer and treatment. For some people, this can be one of the hardest things to cope with. You may feel that by losing your hair you are also losing your identity or you may feel that you don't look 'normal' any more.

Don't be afraid to talk to your cancer nurse or medical social worker about your feelings. If your hospital does not have a medical social worker, your healthcare team can give you advice and help arrange further emotional or psychological support if needed. You can also speak to a nurse in confidence by visiting a Daffodil Centre or by calling our Cancer Nurseline on Freephone 1800 200 700.

Wigs and hairpieces

Having a wig that you are happy with can make you feel better about losing your hair.

At the hospital, your nurse or a member of your healthcare team can advise you about where to go locally for your wig or hairpiece. It's a good idea to do this before you start chemotherapy. It will be easier to find a match for your own hairstyle if the wig fitter can see your natural hair. You will probably also have more energy before you start treatment.

If you need help with finding a wig supplier, ask at the hospital or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

See our website www.cancer.ie for lots of information on hair loss, getting a wig and how to care for your hair and your appearance, during and after treatment.

Coping with changes in your appearance

Your treatment may change your physical appearance permanently or temporarily.

- Surgery might leave you with no breast and/or scarring.
- Some chemotherapy drugs can cause the loss of all your body hair for a short time, including eyelashes, eyebrows and pubic hair. This can be very distressing.
- You may put on weight if you are on hormone therapy or if you are less active due to treatment.

These changes in your body image may be difficult to deal with at first. They may make you self-conscious about everyday things you took for granted. For example, socialising, using a changing room in a shop, being intimate with a partner, or wearing revealing clothing. All these changes can make people react differently towards you. Naturally, this may be upsetting for you. But there are certain things you can do to feel more yourself.



Tips & Hints – Ways to feel more yourself

- Look online for cancer beauty and make up tips and instructional videos
- Check out your local cancer support centre. Many have beauty and image sessions or run Look Good Feel Good workshops
- Ask if the Look Good...Feel Better® programme is available in your hospital. It will give you beauty tips and skincare advice
- Spend time looking for a hairpiece that suits you before you start treatment
- Look for scarves and hats that you like
- Talk to your breast care nurse about what to expect and get advice about how to manage
- Be fitted professionally for your prosthesis and bra and get advice about the best wig for you. Some local cancer support centres have fitting sessions

Bone health and osteoporosis

Some treatments for breast cancer lower the amount of oestrogen in your body. Oestrogen helps to keep your bones healthy and strong. With less oestrogen, bones can become weak and thin, and the condition osteoporosis can develop. Your bones will be more likely to break if you have osteoporosis. Ask your doctor to check if you are at risk of osteoporosis, so you can discuss your options. There is more information on bone health on our website, www.cancer.ie



Tips & Hints – Taking care of your bones

Here are some tips to improve bone strength:

- Take regular exercise such as walking, cycling or working out at the gym.
- Make sure your diet has plenty of calcium-rich foods like cheese, sardines, yogurt and green, leafy vegetables.
- Keep a healthy weight.
- Avoid caffeine and alcohol.
- Stop smoking.
- Make sure you take any supplements or medication prescribed for you.

Will treatment affect my sex life?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. The first months can be very upsetting and full of conflicting emotions, which may affect your sexual feelings for a while.

You may also lose interest in sex if you have a lot of worries on your mind or if you are tired from the effects of treatment.

Physical effects of treatment

Changes to the way your body looks or feels can make you feel less feminine or insecure about your sexuality and your relationship with your partner. You may be anxious about allowing someone to see or touch your body.

Different treatments may affect you in different ways. For example:

Surgery can cause scarring or physical changes that may alter your body image. If you have had reconstruction, you will no longer have the sensitivity you once had in your breast.

Chemotherapy may lower your sex drive (libido) or make you feel too tired or nauseous to think about being intimate.

Radiotherapy may cause your breast and the skin around it to become sore and tender for a while.

Taking about sex and your emotions

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no right or wrong way to feel about your sexuality and sex life and no set time for you to be ready to have sex again.

Your doctor will advise you if you can have sex while on radiotherapy. But you may find it will be some weeks before you feel well enough to have sex again after surgery. Even if you do not feel like having sex, you can still enjoy a loving relationship with your partner. Other forms of intimacy, such as touching, caressing and holding each other, can help you to feel close.

Once you return to your usual routine, your interest in sex should return too. It may even increase, due to a renewed feeling of life. If you haven't been through the menopause, you should use contraception if you have sex during treatment. See below for more information.

If you are single

If you are single, you may feel nervous about starting a new relationship. You may worry about when to tell your new partner about your breast cancer or feel more self-conscious about showing your body. But as you spend time together and feel more comfortable, your trust will increase and you will know when the time feels right.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Asking for advice

If you have any questions about how treatment may affect your sex life, ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to taking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment, even if your periods stop. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

As the cancer may be affected by hormones, you are advised not to take the contraceptive pill. Coils (IUDs) are effective, but the types that use the female hormone progesterone may not be suitable.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or to have more children. This gives your body a chance to recover from the effects of the cancer and its treatment. Getting pregnant after breast cancer does not appear to increase the risk of the cancer coming back.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments. For example, chemotherapy (p 36), hormone therapy (p 41) or other methods that stop your ovaries from working (p 42). Fertility may be affected temporarily – during and for a time after treatment – or permanently, so that you will not be able to have a child in the future. Blood tests after treatment can check if you are fertile or not.

In general the younger you are, the more likely your periods are to return to normal and you may still be able to have children.

The nearer you are to menopause, the less likely it is that your fertility will return after treatment.

Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or embryos before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides this service.

Coping with infertility

Dealing with infertility may not be easy, depending on your age and if you have had children. It can bring feelings of sadness, anger and loss of identity. Infertility is especially hard if you had plans to start a family in the future, or to have more children. It can help to share

your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

What follow-up will I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up mainly involves a consultation with your doctor and a physical examination. You will also have a mammogram once a year.

At first you will see your consultant every 3-6 months, but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget anything important.

If you are between check-ups and have a symptom or problem that is worrying you, tell your doctor or nurse. Make an appointment to see him or her as soon as possible.

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with side-effects
- Keep up your energy and strength

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back. A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications on healthy living.

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given **in addition to** standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used **instead of** standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments...

Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

More information

To find out more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie



Coping and emotions

How can I cope with my feelings?

People react in different ways when they find out they have cancer. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

- Shock and disbelief
- Denial
- Blame and guilt
- Fear and uncertainty
- Anger
- Withdrawal and isolation
- Loss of control
- Resentment
- Sorrow and sadness

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.



Younger women

Breast cancer normally affects women over the age of 50. If you are younger, your diagnosis may come as an even greater shock and cause you extra worries. For example you may want to have a child later in life and worry how your diagnosis might affect this. You may also feel more isolated and alone, as many women with breast cancer will be older than you and at a different stage in their life. If you are finding it hard to cope, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk in confidence or to get advice and support.

Email cancernurseline@irishcancer.ie

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It is not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Free counselling is available at some local cancer support centres. To find out more about counselling, call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.



Ways to get support

Find out about cancer support services in your area: There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 71 for more about cancer support services.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

Join a support or educational group: Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Get one-to-one support: The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

Get online support: There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through: It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people, spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

How can I help myself?

Here is a list of things to help make you feel more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Use your support network: Doing things for yourself can help you to feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from the people who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends: Don't keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you're feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about your cancer and treatment: Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Eat well: Try to eat as well as you can. Have lots of different types of foods with plenty of fresh fruit and vegetables.

Get some exercise: Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques: Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres have classes to help you learn these techniques.

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 55 for more information on complementary therapies.

Accept change in your life: Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs: Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Keep busy: Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Try to cope day by day: Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.



Positive emotions



A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too.

The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what's important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

How can my family and friends help?

Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.

Advice for carers

Caring for someone who has had treatment for breast cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

Coping with both the practical and emotional issues of treatment can be hard. Here are some things that can help to make life a little easier.

Caring for someone with cancer

Learn about cancer: Learn more about breast cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Talk to the dietitian: If your relative or friend has had major surgery, talk to the dietitian before the discharge date. He or she will give you useful advice on the best foods and how to prepare them so that they can be easily swallowed.

Encourage your relative or friend: At first they may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Support for you

Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information.



Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you sometimes don't feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it's just a walk to the shops. Ideally, you should also try to organise a longer break, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Find carers support organisations or local cancer support centres: Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700 and ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Talking to children and teenagers

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, or feel guilty that you can't do activities with your children, or that you're letting them down. You may also worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

You may feel it is best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.



The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It is also available on our website www.cancer.ie.

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time for you to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months. You may also still be dealing with side effects of your treatment, like fatigue and hot flushes.

Feelings you may have include:

Fear of cancer coming back and worrying about every small symptom

Loneliness without the company and support of your medical team and fellow patients

Stress at having to deal with concerns such as your finances, going back to work and family issues that may have been on hold during your treatment

Isolation or guilt if your family and friends expect you to get back to normal before you are ready

Anxiety and self-doubt about sexual and romantic relationships

Anger at what has happened and the effect on you and your loved ones

Depression or sadness

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie/coping/life-after-cancer-treatment

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 59 for other ways to get support.



Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like breast prostheses and wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It is important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some help towards travel costs. See page 70 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: www.cancer.ie

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 71 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our **publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.



If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Helpful books

The Irish Cancer Society has a wide range of information on preventing cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue



Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Taking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Managing the Financial Impact of Cancer. A Guide for Patients and their Families.



Questions to ask your doctor

Here is a list of questions you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

- Is this a specialist breast unit?
- What type of breast cancer do I have? Where exactly is it?
- What type of treatment do I need? Why is this one better for me?
- Are there other treatment options?
- What side-effects or after-effects will I get?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- Is there anything I can do to help myself during treatment?
- Should I eat special foods?
- Will treatment affect my fertility?
- When is a suitable time to have breast reconstruction surgery?

What does that word mean?

| | |
|---------------------------------|---|
| Adjuvant treatment | Treatment given soon after surgery when a diagnosis of cancer is made. |
| Alopecia | Loss of hair where you normally have hair. |
| Anaemia | Fewer red blood cells or haemoglobin. |
| Biopsy | Removing a small amount of tissue from your body to find out if cancer cells are present. |
| Blood count | A blood test that checks the number of different cells in a sample of your blood. |
| Cells | The building blocks that make up your body. They can only be seen under a microscope. |
| Fatigue | Ongoing tiredness, often not relieved by rest. |
| Hereditary breast cancer | A rare breast cancer that runs in families cancer when a faulty gene is passed on by either parent. |
| Immune system | Your body's natural defence against disease and infection. |
| Lumpectomy | Surgery to remove the cancer and a small amount of normal tissue around it. |
| Lymph | A yellow fluid containing cells called lymphocytes which fight disease and infection. |
| Lymph nodes | Small glands scattered along vessels of your lymphatic system. They may become enlarged due to infection or cancer cells. |

| | |
|-----------------------------|--|
| Metastasis | The spread of cancer from one part of your body to other tissues and organs. |
| Oncology | The study of cancer. |
| Recurrence | When cancer comes back after treatment. It can come back in the same place as the original one or in a different part of your body. |
| Sentinel node biopsy | Removing and examining the first lymph node likely to be affected by cancer. |
| Seroma | A collection of fluid that can build up under your wound after breast surgery. |
| Staging | A series of tests that measure the size and extent of cancer. |
| Surgical oncologist | A surgeon who specialises in the treatment of patients with cancer. |
| Triple negative | Breast cancer cells that are examined in the breast cancer laboratory and which do not have oestrogen receptors, progesterone receptors, or large numbers of HER2 protein. |
| Tumour | An abnormal mass of tissue caused by an overgrowth of cells. It may be benign (not cancerous) or malignant (cancerous). |

Join the Irish Cancer Society team



If you want to make a difference to people affected by cancer, join our team!

There are lots of ways to help:

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it is like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments and suggestions.

Please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Email: cancernurseline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

