

Understanding

Breast cancer

Caring for people with cancer



Understanding

Breast cancer

This booklet has information on:

- Treatment for breast cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

If you have metastatic (secondary) breast cancer, please call our Support Line for a copy of our booklet ***Understanding Metastatic (secondary) breast cancer***, or download it from www.cancer.ie

Useful numbers

Breast care nurse/clinical nurse specialist

Family doctor (GP)

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Oncology day ward

Hospital records number (MRN)



Contents

| | |
|------------------------------------|-----|
| About breast cancer | 7 |
| Diagnosis and tests | 15 |
| Treating breast cancer | 29 |
| Types of treatment | 43 |
| Managing side-effects and symptoms | 73 |
| After treatment | 91 |
| Coping and emotions | 97 |
| Supporting someone with cancer | 105 |
| Support resources | 111 |
| What does that word mean? | 124 |
| Questions to ask your doctor | 126 |

Fast facts

What kind of treatment will I have? Page 29

Surgery, radiotherapy, chemotherapy and targeted therapies are the main treatments for breast cancer.

Are there side-effects from treatment? Page 73

Any side-effects will depend on your cancer and the type of treatment you have. For example, breast cancer chemotherapy drugs usually cause hair loss.

You can read about the treatments to learn more about their side-effects and possible complications. For advice on coping with side-effects, see page 73. There is also a section there on coping with hair loss.

There are treatments to help with most side-effects so tell your doctor or nurse. Don't suffer in silence.

Will I be OK?

Page 26

Most early stage breast cancer can be successfully treated. The best thing to do is to ask your consultant about your own situation.



We're here for you

Page 116

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre
- Email us: supportline@irishcancer.ie

See page 116 for more about our services.



Support Line Freephone 1800 200 700

Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

In the booklet we speak mainly about women and breast cancer. However, men too can be diagnosed with any of the types of breast cancer we describe.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

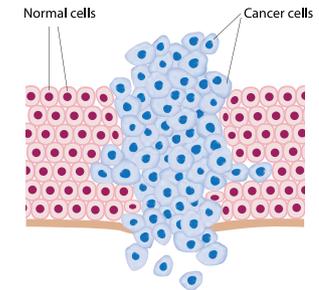
We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

About breast cancer

| | |
|--------------------------------------|----|
| What is cancer? | 9 |
| What is the lymphatic system? | 9 |
| What are the breasts? | 10 |
| What is breast cancer? | 10 |
| What are the types of breast cancer? | 10 |
| What causes cancer? | 14 |
| How common is breast cancer? | 14 |

What is cancer?

- **Cancer is a disease of the body's cells**
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

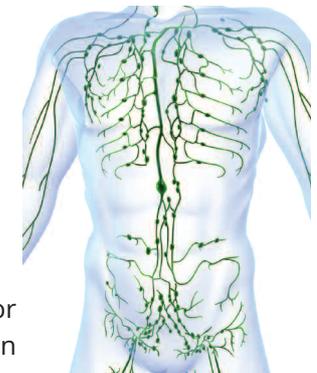


- **Cancers are named after the organ or cell where the cancer starts**
Breast cancer starts in cells in the breast.

- **Cancers sometimes spread**
If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new tumour. This is called metastasis.

What is the lymphatic system?

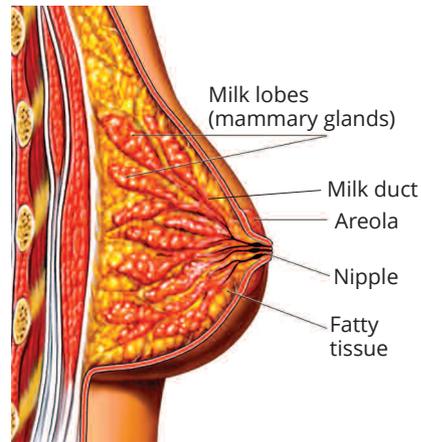
- The lymphatic system protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes they can become swollen.



Support Line Freephone 1800 200 700

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 are part of the lymphatic system (see page 9).



What is breast cancer?

Breast cancer is when the cells in your breast tissue change and grow in an abnormal way. Breast cancer can affect both men and women, but it's rare in men.

What are the types of breast cancer?

Breast cancer may be described as:

- Non-invasive breast cancer
- Invasive breast cancer

To find out which type you have, the laboratory doctor (pathologist) will look at your cells under the microscope.

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 can spread 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. This redness is caused by cancer cells blocking tiny channels in the breast tissue called lymph channels. This is a rare type of cancer, accounting for only 1 or 2 in every 100 breast cancers. You will need to have chemotherapy before surgery with this type of cancer.

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.

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 Support Line on 1800 200 700 or visit a Daffodil Centre for more details.



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.

Receptor information can be used to describe breast cancer:

Hormone / Oestrogen receptor-positive breast cancer: The cancer cells have extra oestrogen or progesterone receptors.

Hormone receptor-negative breast cancer: The cancer cells don't have any extra oestrogen or progesterone receptors.

HER2 positive breast cancer: The cancer cells have large numbers of the HER2 protein on their surface, which can help the cancer cells to grow.

HER2 negative breast cancer: The cancer cells don't have extra HER2 protein on their surface.

Triple negative breast cancer: The cancer cells don't have receptors (proteins) on their surface for the hormones oestrogen, progesterone or HER2. This occurs in about 1 in 5 women with breast cancer and often in younger women.

Triple-positive breast cancer: The 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 or targeted therapies will be most effective for you.

What causes cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for breast cancer, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

Family history of cancer



A faulty gene can lead to breast cancers in a very small number of women. Faulty genes that have been linked to breast cancer include BRCA1 and BRCA2. If any of your close family members are concerned about developing breast cancer, they should talk to their family doctor, who can advise them if they might benefit from genetic testing.

How common is breast cancer?

Breast cancer is the second most common cancer in women in Ireland – with about 3,000 women and 25 men affected each year.

Support Line Freephone 1800 200 700

Diagnosis and tests

| | |
|---|----|
| Being diagnosed with breast cancer | 17 |
| What tests will I have? | 19 |
| How is breast cancer staged and graded? | 24 |
| What are the stages of breast cancer? | 25 |
| How is breast cancer graded? | 25 |
| Asking about your prognosis | 26 |

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

However you feel,
you are not alone.

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

- Ask to speak to the cancer (oncology) liaison nurse or the 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 – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community
- Go to your local cancer support centre. For more information, see page 122.

Email: supportline@irishcancer.ie

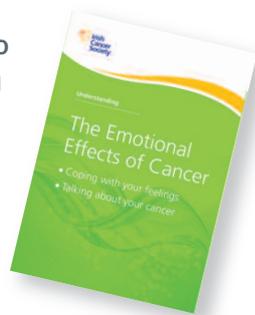
Telling people about your diagnosis



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 Support Line 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 ***Understanding the Emotional Effects of Cancer***. 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 a diagnosis of breast cancer, tests you may have include a lymph node ultrasound scan, biopsy, blood tests, X-rays, MRI scan, and possibly a CT scan, bone scan, liver ultrasound and PET scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

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



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 the 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. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.



An MRI can also be noisy, but you will be given earplugs/headphones 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 a medical device in your body, like a pacemaker or metal pin, you may not be suitable for the test. Usually you can go home soon after the scan.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. 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.

The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.



Bone scan

For this test a tiny amount of a mildly radioactive substance is injected into a vein, usually in your arm. After the injection you will have to wait about 3 hours, then a scan is 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. 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

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into a vein in your arm. An hour or so later you will have a scan. The radioactivity can

highlight cancer cells in your body. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

PET is safe to use and there are no side-effects. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

Waiting for test results



It usually takes over 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 Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



How is breast cancer staged and graded?

- 
- Staging cancer means finding out its size and if it has spread.
 - Grading means looking at the cancer cells to see how they might grow.
 - Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis are usually done to help the doctor to give your cancer a stage and a grade.

- **Staging** describes where the cancer is in your body – its size and if it has spread.
- **Grading** describes the cancer cells – what they look like and how they might grow.

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?

Staging normally refers to:

The size of the tumour (T)

If there is cancer in the lymph nodes (N)

N0 means no lymph nodes are affected. If cancer has spread to the lymph nodes (positive nodes) the N will have a number to describe how many lymph nodes are affected. NX means the doctors cannot tell if the nodes are affected.

If the cancer has spread (metastasis) (M):

M1 means the cancer has spread (metastatised) to other organs and M0 means it hasn't.

Your doctor often uses this information to give your cancer a number stage – from 0 to 4.

A higher number, such as stage 4, means the cancer has spread to other parts of the body. Some stages are further divided into stage A and B.

In general, the lower the number, the less the cancer has spread.

What are the stages of breast cancer?

Stage 0: Non-invasive breast cancer, for example, DCIS

Stage 1: The cancer is found only in your breast

Stage 2: The cancer is found in 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.

Asking about your prognosis



Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



Should I ask about my 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.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you,** if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@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.



Treating breast cancer

| | |
|----------------------------------|----|
| How is breast cancer treated? | 31 |
| Deciding on treatment | 32 |
| Who will be involved in my care? | 33 |
| Giving consent for treatment | 36 |
| Waiting for treatment to start | 37 |
| How can I help myself? | 38 |

How is breast cancer treated?

- 
- Surgery, radiotherapy, chemotherapy, hormone therapy and targeted therapies are the main treatments for breast cancer.
 - A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- 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 have hormone-receptors or HER2 protein receptors (see page 13)

What types of treatment are used?

The main treatments for breast cancer are:

- Surgery
- Radiotherapy
- Chemotherapy
- Hormone therapy
- Targeted therapies

The treatments may be used alone or in combination with each other, and not necessarily in this order. See page 43 for more about the types of treatment.

Specialist cancer centres

Breast cancer is treated in specialist 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.



Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. If you do forget to ask a question or need more explanations, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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 treating doctor or your GP can 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 a particular 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.

Who will be involved in my care?

Some of the following may be involved in your care at the hospital. Usually a team of specialists (multi-disciplinary team) will decide your treatment.

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 healthcare professional 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. They give information and support 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. They can do different types of breast reconstruction.

Cancer genetics consultant/specialist: A specialist in genetic testing – they 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 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 can advise you on diet during your illness and on how to use your 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.

Pharmacists: Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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.

Giving consent for treatment

Before you start any treatment, 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
- Possible side-effects from 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.

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 scans or treatment for a few weeks does not usually affect how well the treatment works.

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

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control.



How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well



Eating as well as possible can help you during your treatment. It can help you to:

- Maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Recover more quickly

Ask to talk to the dietitian at the hospital for advice on the best diet for you.

You can also read our booklet *Diet and Cancer*. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website www.cancer.ie

Be active

Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you.

Be careful not to overdo it at the beginning – build up gradually.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers have fewer complications from surgery, chemotherapy and radiation.
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have smoking cessation officers who can help and support you.

Other ways to help yourself

Get 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. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

Don't keep any worries or 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. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.



Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

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.

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.





Types of treatment

| | |
|--------------------------------------|----|
| Surgery | 45 |
| Radiotherapy | 55 |
| Chemotherapy | 58 |
| Targeted therapies | 64 |
| Hormone therapy | 66 |
| Treatment for cancer that has spread | 70 |
| Clinical trials | 71 |

Surgery

- Surgery means removing a tumour.
- Surgery can often cure early-stage breast cancer.
- There are different types of surgery for breast cancer.

Most people who are treated for breast cancer have some type of breast surgery. Your surgeon will discuss with you the most suitable type of surgery. There are two main types:

- **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 (multi-focal disease).

Breast-conserving surgery

In this type of surgery, only part of your breast is removed. You will need radiotherapy treatment afterwards. This will help reduce the risk of the cancer coming back in the breast.

There are different types of breast-conserving surgery. You will have a scar after this kind of surgery. The scar may not be directly over the cancer.

Lumpectomy/wide local excision

These surgeries remove only the breast lump and some normal tissue around it.

If the lump is small, you may need to have a fine wire/clip inserted (wire localisation/clip localisation) into the breast before surgery. The wire is inserted under local anaesthetic by a radiologist, during a mammogram or ultrasound. This wire is used to mark the area to be removed. It is then removed along with the cancerous area during surgery.

Checking the margins

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. Around 1 in 7 women will need this operation, which is called a re-excision of margins. This may have to be done more than once. If your surgeon cannot remove enough breast tissue to get clear margins, you may need to have a mastectomy.

Mastectomy

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 52). 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 53 for more on breast reconstruction. Talk to a cancer nurse on our Support Line 1800 200 700 or download the booklet *Understanding Breast Reconstruction* from our website www.cancer.ie.



Bilateral mastectomy - removing both breasts

Some women may need to have both breasts removed. This is called a bilateral 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 someone who has had bilateral surgery.

Call our Support Line 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 also 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 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 9). 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 next page). For more about lymphoedema, see page 77.

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 1-3 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 results.

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, you may need further surgery to the lymph nodes. 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 may need to 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. The hospital physiotherapist will show you how to do some special arm exercises.

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.

There is a small risk of swelling in your arm (lymphoedema). This can happen any time after the operation. See page 77 for more about lymphoedema.

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. The nurses usually remove these a week to 10 days after the operation.

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, you might need to stay for several days or longer.

After an axillary clearance, your stay is usually longer. 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 breast care 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 painkillers can be prescribed.

Stiffness

A physiotherapist will advise you on the arm exercises you need to do to prevent your arm and shoulder joint from getting stiff. There are usually special exercises for 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 it is gradually reabsorbed by the body.

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 Support Line on Freephone 1800 200 700 to talk to a cancer nurse in confidence. Or you can speak to a nurse in a Daffodil Centre. See page 97 for more about feelings and emotions.

Breast prostheses

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



Prostheses come in a wide variety of 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 you. The most common type of prosthesis rests against your chest wall and is held in place by your bra, but there are 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 Support Line 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

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 93.

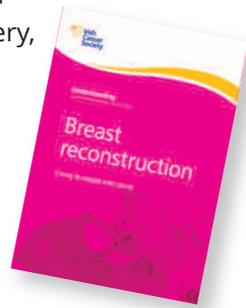
When you get home, take things easy for a while. You may feel physically and emotionally exhausted. Try to have long rest periods and eat a well-balanced diet. You will probably be advised not to lift or carry anything heavy or drive for a few weeks.

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. Or a combination of these techniques can be used.

Sometimes reconstruction 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. You can call our Support Line 1800 200 700 for a copy of our booklet ***Understanding Breast Reconstruction***, or pick one up at your local Daffodil Centre. For more information, see our website www.cancer.ie.



Why have 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. 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.

Support Line Freephone 1800 200 700

Radiotherapy



- Radiotherapy uses high-energy rays to kill cancer cells.
- You normally have treatment every weekday for a number of weeks.
- Side-effects affect the area of the body where the radiotherapy is aimed.
- Side-effects normally go once your treatment is over, but some can last a long time or develop later on.

Radiotherapy 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:

- After surgery to destroy small amounts of the cancer that may be left. This is called adjuvant treatment.
- With chemotherapy to make the treatment work better.
- To control and relieve symptoms of advanced cancer. This is called palliative radiotherapy.

Radiotherapy can be given in two ways:

External beam radiotherapy: The radiation comes from machines which aim rays directly at your tumour or the tumour site. The machines are called linear accelerators.

Internal radiotherapy (brachytherapy): The radiation source is placed inside your body in special applicators on or near your tumour.

You may have both external and internal radiotherapy.

Planning your radiotherapy 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.

External radiotherapy

You will have a CT scan to pinpoint the area to be treated. 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.



How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (6 to 8 weeks) or between 1 and 10 doses for treatment to relieve your symptoms.

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

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different hospital from where you had surgery or chemotherapy.

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 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 our Support Line on 1800 200 700 or visit a Daffodil Centre.

Side-effects of treatment

Any side-effects tend to affect the area of the body being treated. When the breast is being treated, the most common side-effects are:

- Skin changes/irritation, e.g. nipple soreness, changes to the appearance of the skin or peeling, flaking skin in the treated area
- Tiredness (fatigue)
- Indigestion

How severe these side-effects are will vary from person to person, depending on the amount of treatment you receive. 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 77)
- Breast swelling and pain, which 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 our booklet *Understanding Radiotherapy*, call our Support Line on 100 200 700 or visit a Daffodil Centre.

Chemotherapy



- Chemotherapy uses drugs to kill cancer cells.
- Possible side-effects include nausea and vomiting, infection, fatigue, anaemia, hair loss and mouth sores.
- Side-effects normally get better after treatment ends.

Chemotherapy is a treatment that uses drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy drugs may be given:

- 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.

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), or lymph node positive (with cancer cells in 1-3 lymph nodes) oestrogen-receptor-positive (ER+) or HER2 negative (see page 13).

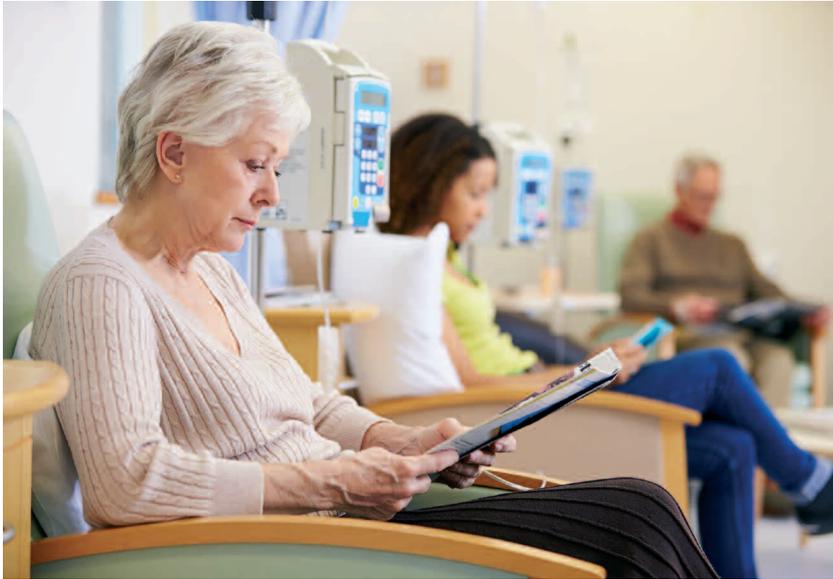
For more information on this test, and information on understanding recurrence scores, see our website www.cancer.ie

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and 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 (by drip or pump). It may also be given in tablet form. Your treatment will normally 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.

If you know the name of your chemotherapy drug, you can visit the Health Product Regulatory Authority's website at www.hpra.ie for information about the drug and possible side-effects.

Email: supportline@irishcancer.ie

Understanding your drug treatment



It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

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:

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 75.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low 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.

Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help your blood to clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. 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 many 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 menopause, such as hot flushes. Sometimes chemotherapy brings on an early menopause. For more about managing menopausal symptoms see page 78.

Hair loss (alopecia)

Some chemotherapy drugs can 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. Hair will grow back after you stop chemo. See page 81 for more about hair loss.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

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. Tell your doctor if you have 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 87.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given contact details of who to contact before you start your treatment.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre. There's advice on coping with side-effects on our website, www.cancer.ie

Targeted therapies



- Targeted therapies are drugs that target certain parts of the cancer cells that make them different from other cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies work with your body. They can help fight cancer and stop it spreading. With breast cancer, targeted therapies are used for women who have HER2 receptors on the surface of their breast cancer cells.

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

Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cells to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

The type of targeted therapy most commonly used for breast cancer is monoclonal antibodies. For example, trastuzumab and pertuzumab. These drugs are only used for HER2 positive breast cancer. The drugs block the receptors on the cells, so that HER2 proteins can't attach to the cells and help them to grow. They also help the immune system to target and kill the cancer cells. Targeted therapy drugs are usually given into a vein through a drip or as an injection. Other drugs may be given as a tablet.

Side-effects

Side-effects depend on the drugs being used and vary from person to person.

Common side-effects include:

- Higher risk of getting an infection
- Vision changes (blurred vision, double vision, flashing lights)
- Diarrhoea or constipation
- Loss of appetite
- Feeling sick
- Feeling very tired (fatigue)
- Heart problems – for example, changes to your blood pressure or heart rhythm, or your heart muscle not working properly.

Your doctor and nurse will explain your treatment to you 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 you are having any symptoms that are troubling you.

Support Line Freephone 1800 200 700

Trials of new targeted therapies



New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 72). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Hormone therapy

Some women have extra receptors on the surface of their breast cancer cells that attach to the female hormone oestrogen. This is called oestrogen- or hormone-receptor positive cancer (see page 13). 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.
- As a primary therapy when 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.

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 goselerin (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) – women whose ovaries no longer produce oestrogen. 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 – the main source of oestrogen for pre-menopausal women – are removed. Smaller amounts of oestrogen will still be produced by other cells in the body. Removal of your ovaries 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 78.

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 83.

Blood clotting

Some treatments slightly increase the risk of blood clotting. Tell your doctor if you have any 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 between periods or after sex while you are having treatment.

Bone loss and pain

Some drugs may increase bone loss and cause pains and aches in your muscles 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).



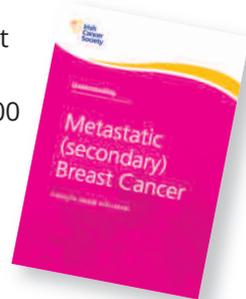
Treatment for cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed.

If your cancer has spread, it can still be treated. Treatment aims to control the disease for as long as possible. There is a range of treatment options for most advanced cancers, and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 71).

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



Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

Clinical trials

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

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. 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.

Drugs that are used in a clinical trial have been through years of testing before they are given to patients. However, because the drugs are still in trial, patients taking part will be monitored even more closely than normal and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For 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 Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at www.cancertrials.ie



Managing side-effects and symptoms

| | |
|--|----|
| How can I cope with fatigue? | 75 |
| Lymphoedema | 77 |
| Managing menopausal symptoms | 78 |
| Coping with changes in your appearance | 82 |
| Will treatment affect my sex life? | 84 |
| Will treatment affect my fertility? | 87 |
| Cancer and complementary therapies | 89 |

How can I cope with fatigue?

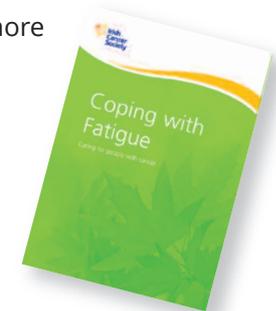
Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Fatigue when you have cancer 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

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.

Our booklet ***Coping with Fatigue*** has more advice. Call our Support Line on 1800 200 700 or call into a Daffodil Centre for a free copy. It's also on our website www.cancer.ie



Hints & Tips – 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 such as caffeine and alcohol before bedtime.
- Try complementary therapies if your doctor says they're safe for you. For example, meditation, acupuncture or massage.



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 the treated 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

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 Support Line on 1800 200 700 or by visiting a Daffodil Centre.

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

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 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 at 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.

Hints & Tips – 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). This is not recommended after a diagnosis of hormone-sensitive breast cancer
- Therapies such as reflexology, massage, meditation and, aromatherapy can help relieve menopausal symptoms for some people. Always discuss complementary therapies with your cancer specialist or GP before starting
- Relaxation techniques like meditation and yoga
- Emotional support from counsellors and support groups

Coping with hot flushes

- Avoid warm areas and use an electric fan to lower your skin temperature.
- Avoid spicy foods, caffeine, alcohol, sugar and hot drinks.
- Avoid hot baths or showers, as they may trigger a hot flush.
- Wear cotton or 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. It may be possible to reduce or delay hair loss by using a 'cold cap'. This is also known as scalp cooling. A cold cap is a hat you wear during chemotherapy to reduce blood flow to your scalp so less of the drug reaches your scalp. The cold cap does not always prevent hair loss and it only blocks the action of certain drugs. Your doctor or nurse can tell you whether a cold cap is available in your hospital and if it might work for you.

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 Support Line 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 Support Line 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.

Hints & Tips – ways to feel more yourself

- Look online for cancer beauty and make up tips and instructional videos. For example, there are products and techniques to help if you've lost your eyebrows or eyelashes.
- Check out your local cancer support centre. Many have beauty and image sessions or run 'look 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 thinning and bone health on our website, www.cancer.ie

Tips and Hints: taking care of your bones

- Take regular exercise such as walking, cycling or working out at the gym. Your doctor can advise you on the best exercise for you.
- 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.



Talking 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. They 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.

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.

If you haven't been through the menopause, you should use contraception if you have sex. See the next page for more information.

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

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.

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 talking about these matters and will give you advice. You can also call our Support Line 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 supportline@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 (page 58), hormone therapy (page 66) or other methods that stop your ovaries from working (page 68). 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. For example, it may be possible to freeze your eggs or embryos before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this may be an option for you.

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, 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 Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and mindfulness.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie



After treatment

| | |
|-----------------------------|----|
| What follow-up will I need? | 93 |
| Life after treatment | 94 |
| Living a healthy lifestyle | 95 |

What follow-up will I need?

After your cancer treatment has ended you will still need to have regular check-ups. This is called follow-up. The follow-up may involve having a physical examination, and 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, so you don't forget anything.

It's important to attend your follow-up appointments as they will allow your doctor to check for signs of the cancer coming back (recurrence) and to help with any side-effects that you may have. He or she can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the accident and emergency department at the hospital.

Support Line Freephone 1800 200 700

Life after treatment

It can take some time 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.

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 things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- **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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 101 for other ways to get emotional support.

What if the cancer comes back?

If cancer comes back, it can often be treated again. Your cancer doctor will advise you on what your treatment options are.

Living a healthy lifestyle



Many people want to make positive changes to their lives after a diagnosis of breast cancer. 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

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Protecting yourself from the sun
- Avoiding alcohol

If you want more information or advice, call our Support Line 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.



Coping and emotions

| | |
|----------------------------------|-----|
| How can I cope with my feelings? | 99 |
| Ways to get emotional support | 101 |
| You and your family | 104 |

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

Our booklet *Understanding the Emotional Effects of Cancer* discusses in detail how you may be feeling. Call our Support Line 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 children 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 Support Line on 1800 200 700 or visit a Daffodil Centre to talk in confidence or to get advice and support.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, 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, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

Ways to get emotional support



Find out about cancer support services in your area

Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 122 for more about cancer support services.

'Counselling has helped me with every part of my life. I feel I have a future now.'

Join a support or educational group

You might find it 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.

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.

Survivor Support

Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Get online support

Special websites called online communities let you 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 worries. 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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Positive feelings

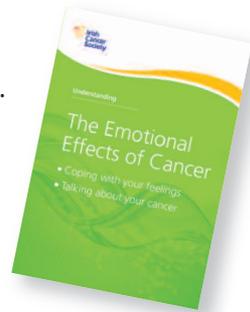
In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.



You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Understanding the Emotional Effects of Cancer* can help to you find ways to talk about your cancer and to ask for the help and support you need.



Changing relationships



You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.

Supporting someone with cancer

| | |
|------------------------------------|-----|
| Supporting someone with cancer | 107 |
| How to talk to someone with cancer | 108 |
| Support for you | 109 |

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.



Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 101.

Find out about support for carers

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 Support Line on 1800 200 700.

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



Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for Someone with Cancer*** has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring



Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie

Email: supportline@irishcancer.ie



Support resources

Coping with the financial impact of cancer 113

Irish Cancer Society services 116

Local cancer support services 122

Coping with the financial impact of cancer

- 
- If you have cancer you may not be able to work for a time. You may also have extra expenses.
 - You may have to pay for some of your cancer treatment.
 - You might be entitled to certain social welfare payments.
 - There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that 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 harder for you to deal with cancer if you're 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
- Medical aids and equipment (appliances), like 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. If you are over 70, you can get a free GP visit card.

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 don't 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's important to contact your insurance company before starting treatment to check you're covered.

Benefits and allowances

There are benefits 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 074 000
- **Department of Employment Affairs and Social Protection** – 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 money problems

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 give some help towards travel costs in certain cases. See page 119 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer*. 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. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living-at-home and nursing home supports.

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:

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. Our Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on supportline@irishcancer.ie or visit our Online Community at www.cancer.ie

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



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- End-of-life services
- Chemotherapy group education sessions
- Lifestyle and cancer prevention
- Emotional support
- Local cancer support groups and centres
- Practical entitlements and services
- Living with and beyond cancer

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

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 and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality confidential support in a location that's convenient to them.

The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to www.cancer.ie and search 'Find Support'.

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 National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly 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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

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 Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line 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 one-to-one 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 Support Line 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>

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, 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). |

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?

The Irish Cancer Society has produced this booklet 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 their time and expertise to previous editions of this booklet.

BREAST CANCER ADVISERS

Dr Megan Greally, Consultant Medical Oncologist
Ruth Prichard, FRCSI, Consultant Breast Surgeon
Antonia Tierney, Clinical Nurse Specialist in Oncology Care

CONTRIBUTOR

Donna Spillane, Daffodil Centre Nurse

EDITOR

Sarah Lane

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

- *Clinical Practice Guidelines in Oncology: Breast Cancer*. National Comprehensive Cancer Network, 2012.
- Locally recurrent or metastatic breast cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. European Society for Medical Oncology Guidelines Working Group, *Annals of Oncology* 22: vi25–vi30, 2011.
- International guidelines for management of metastatic breast cancer: can metastatic breast cancer be cured? European School of Oncology Metastatic Breast Cancer Task Force, *Journal of the National Cancer Institute* 102, 456-63, 2010.
- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2016 with estimates for 2016-2018*: Annual report of the National Cancer Registry (2018)
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (editor), 9th edn. Lippincott Williams & Wilkins, 2011.
- *Cancer Nursing: Principles and Practice*, CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 7th Ed (2011).
- *The Chemotherapy Source Book*, M Perry. Lippincott Williams and Wilkins, 5th Ed (2012).

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2012. Revised 2017, 2020 Next revision: 2022

Product or brand names that appear in this booklet 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.

Join the Irish Cancer Society team

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

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's 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 Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

