

Understanding

Cancer of the Breast

Caring for people with cancer



Understanding

Cancer of the Breast

This booklet has been written to help you understand more about breast cancer. It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment, and the key aspects of living with it.

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



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Surgeon	Tel:
Medical oncologist	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Medical social worker	Tel:
Emergency number	Tel:

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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Introduction

This booklet has been written to help you learn more about breast cancer. It describes how breast cancer is diagnosed and the range of treatments that you may be offered. We hope it answers some of the questions you may have.

We cannot advise you about which treatment to choose. Only you can make this decision, along with your specialist doctor, when all your test results are ready. However, we can help you find out more about some of the ways used to treat this cancer and the side-effects that may occur.

This booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet there is a list of books you may find useful. There is also a list of websites and special groups to help and support you at this time.

If reading this booklet helps, why not share it with your family and friends who might find it helpful too. The more they know about your illness the more they can help you through your diagnosis.

>>> Reading this booklet

Remember you do not need to know everything about breast cancer straight away. Read a section about a particular item as it happens to you. Then when you feel ready to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse.

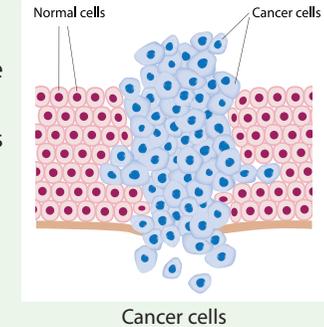


You can also call the freefone National Cancer Helpline on 1800 200 700, if you wish. It is open Monday to Thursday 9am–7pm and Fridays 9am–5pm. Or if you prefer, you can also visit a Daffodil Centre if one is available in your hospital. See page 70 for more about Daffodil Centres.

About breast cancer

>>> What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer starts growing. For example, prostate cancer, breast cancer and leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep your body healthy. But with cancer, abnormal cells grow without control. Groups of abnormal cells can then form a growth or tumour.



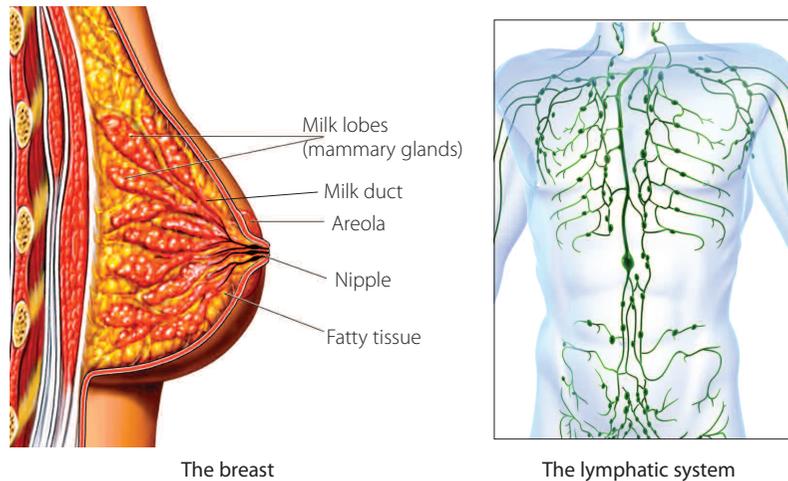
Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body but malignant tumours do. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. This is called a metastasis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

What are the breasts?

Your breasts are made up of different types of tissue including fat, connective tissue and gland tissue. The gland tissue is divided into milk lobes and milk ducts. During and after pregnancy, milk is made and stored by the lobes and carried to the nipple by the ducts.

Your breasts are rarely the same size as each other. They may feel different at different times of the menstrual cycle, sometimes becoming lumpy just before your period. Under your skin, a 'tail' of breast tissue extends into your armpit (axilla). The armpits also contain a collection of lymph nodes (glands) that make up part of the lymphatic system. The lymphatic system is a network of lymph nodes connected throughout your body by tiny vessels called lymph vessels.

A yellow fluid (lymph) flows through the lymphatic system. Lymph contains cells called lymphocytes that fight disease and infection.



What is breast cancer?

Breast cancer occurs when the cells in your breast tissue grow in an abnormal way. It can affect how your breasts work normally. There are many different kinds of breast cancer, which are usually divided into two types: ductal carcinoma in situ (DCIS) and invasive breast cancer. See page 12 for more details.

How common is breast cancer?

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

What causes breast cancer?

The exact cause of breast cancer is unknown. But there are certain things called risk factors that can increase your chance of getting the disease. These include:

- **Gender:** Breast cancer is 100 times more common in women than in men.

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

If you feel that you or other family members may be at higher risk of developing breast cancer, do talk to your healthcare team. Members of your family may be referred to a family history clinic at a specialist breast unit. Here they can discuss screening and referral to a genetics clinic.

What are the symptoms of breast cancer?

In most cases, cancer of the breast is first noticed as a lump in your breast. However, other signs to be aware of are:

- A change in size or shape – one breast may become larger than the other
- Changes in the nipple – in direction or shape, pulled in or flattened, or an unusual discharge
- Changes on or around the nipple – rash, flaky or crusted skin
- Changes in the skin – dimpling, puckering or redness
- Swelling in your armpit or around your collarbone

- A lump of any size or thickening in your breast
- Constant pain in one part of your breast

Pain in both your breasts is not usually a symptom of breast cancer. In fact, many healthy women find that their breasts feel lumpy and tender before a period. Some types of benign (non-cancerous) breast lumps can also be painful.

How is breast cancer diagnosed?

First, visit your family doctor (GP) who will examine you and decide if you need to have tests. If your GP has any concerns about your symptoms, he or she will refer you to a specialist breast clinic, which is based in a hospital. Your GP will refer you by completing a form that can be faxed or posted, or you might be asked to bring the form to the hospital yourself. At the hospital, you will see the breast consultant who may do triple assessment. This means there are three different ways to check your breasts.

- 1 First, your doctor will take a medical history. He or she will then examine your breasts and feel for any swellings in your breast, underarms or base of your neck.
- 2 The next step is usually a mammogram or X-ray of your breast. This is done in the X-ray department. Some patients may need an ultrasound scan instead of a mammogram. In some cases, they have both a mammogram and ultrasound.
- 3 Finally, you may need a biopsy. This involves taking a sample of cells or tissue, which is then examined under a microscope. There are different ways to do the biopsy. For example, a fine needle test or a core biopsy.

If you do not have a lump, you may not need full triple assessment.

Tests that can diagnose breast cancer include:

- Mammography
- Ultrasound scan
- MRI scan
- Needle (core) biopsy
- Stereotactic biopsy
- Excision biopsy
- Wire localisation biopsy

Mammography: Mammograms (breast X-rays) are important tests in the diagnosis of breast cancer. A mammogram is a low-dose X-ray of your breast which can pick up small changes that cannot be felt. Each breast is placed between two special plates and pressure is applied to get the best possible picture.



Some women find mammography uncomfortable or even painful. However, it only lasts a few minutes and is not harmful. A radiographer takes the pictures and a radiologist reads and interprets them.

Ultrasound scan: This test is painless and takes just a few minutes. Ultrasound uses sound waves to build up a picture of the tissues inside your body. It is often used with mammography in specialist breast clinics. A special gel is spread onto your breasts and a small device like a microphone is passed over the area. The echoes from the sound waves are changed into a picture by a computer.

MRI scan: This test is also painless. Magnetic energy is used to take detailed pictures of your breast tissue. The pictures are taken while you are lying down and passing through a kind of tunnel. It is generally used for young women with an increased risk of developing breast cancer. It is also useful for assessing a particular type of breast cancer called lobular breast cancer and for breast abnormalities linked to pregnancy. Very few women need an MRI scan.

Needle biopsy (core biopsy): This test is done in the specialist breast unit. Your doctor takes a small piece of tissue (biopsy) from the breast lump after the area has been numbed with a local anaesthetic. The sample is then sent to the laboratory for examination under a microscope. The test takes about 10 minutes and a small dressing is placed over the area for about a week. The area may be slightly bruised and uncomfortable for a few days. Ask your specialist about simple painkillers you can take at this time.

Marker clips

During a biopsy, tiny wire marker clips might be put into your breast. These will mark the site of your breast cancer more accurately so it can be seen clearly on a mammogram or ultrasound scan. Usually they are placed in your breast before you receive any chemotherapy or hormone therapy before surgery (pre-surgical neoadjuvant treatment). That way the cancer site can still be identified after treatment. Sometimes they are used if a biopsy of a small growth is taken, as it helps the radiologist identify the area later, especially if the area needs to be removed (see wire localisation biopsy). Marker clips can be left in your breast and do not need to be removed. They are entirely safe and most women do not feel them.

Stereotactic biopsy: This test is done in the X-ray department. It is used to take a piece of abnormal tissue seen on a mammogram or an ultrasound but that cannot be felt. Stereotactic biopsy uses a hollow needle guided by X-rays to remove a sample from the abnormal tissue. The sample is then sent to the laboratory for examination under a microscope. Usually several biopsies are taken.

Excision biopsy: This test is done if a benign lump persists, is uncomfortable, or if you choose to have it removed. The whole lump is removed under a general anaesthetic and sent to a laboratory for examination. This may mean an overnight stay in hospital but is more often done in one day.

Wire localisation biopsy: This test is done if you have suspicious calcifications (white spots) seen on a mammogram. Usually you will not have a lump and it will only be picked up through screening mammograms. The radiologist uses a mammogram or ultrasound scan as a guide to put a fine wire into your breast. The wire is carefully secured and left in place until surgery, which is usually the same day. Then a biopsy is taken of this area under general anaesthetic and sent to the laboratory to be examined by a breast pathologist. No further surgery may be needed if all the white spots have been removed and there is no cancer. However, in some cases where there are cancerous white spots, further surgery may be needed.

Further tests

If the tests show that you have breast cancer, your doctor may wish to do some further tests to see if the cancer has spread to other parts of your body. This is known as staging. These tests will help your doctor to decide on the best type of treatment for you. Your doctor will let you know if you need more tests and what they will be. These can vary from a liver ultrasound and bone scan to a PET scan.

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 for a few hours beforehand. Check with your doctor or breast care nurse.

Bone scan: For this test a tiny amount of a mildly radioactive substance is injected into a vein, usually your arm. A scan is then taken of all the bones in your body. Because abnormal bone absorbs more of the radioactive substance than normal bone, the abnormal bone shows up as highlighted areas. After the injection you will have to wait about 3 hours before the scan can be taken. You may want to bring a book or magazine with you, or a friend to keep you company. The level of radioactivity is very low and not harmful to adults. But do avoid babies and young children until the day after the test. The radioactivity disappears within a few hours. You will be given full instructions by hospital staff.

Waiting for test results

Before you leave hospital you may not have the results of all your tests. An appointment will be made to visit the breast clinic within a short time. Obviously the waiting period will be an anxious time for you and it may help to talk about your worries with a partner, close friend or relative.

There are many different types of breast cancer, the most common being invasive ductal carcinoma. For more information on the different types of breast cancer, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre

What are the types of breast cancer?

There are many different types of breast cancer. To find out which type you have, the laboratory doctor called a pathologist will look at your cells under the microscope. This is important for deciding your treatment plan. Breast cancer is usually divided into two types:

- Ductal carcinoma in situ (DCIS)
- Invasive breast cancer

Ductal carcinoma in situ

Ductal carcinoma in situ (DCIS) is the earliest form of breast cancer. It is also called precancerous, intraductal or non-invasive. This means that cancer cells have formed inside the milk ducts but not spread outside them. Most people have no symptoms at all and are usually diagnosed from a mammogram (breast X-ray). For more details on DCIS, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, and ask for a copy of the DCIS factsheet.

Invasive breast cancer

If your breast cancer cells have moved beyond the milk ducts and spread into the surrounding breast tissue, it is called invasive. There are several different types of invasive breast cancer. These include:

Invasive ductal carcinoma: This is the most common type of breast cancer. It is also called infiltrating ductal carcinoma. Other names for it are invasive or infiltrating breast cancer. It starts developing 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. It can affect women at any age, but is more common as women grow older.

Invasive lobular breast cancer: This type starts in cells that make up the lobules at the end of the milk ducts. Invasive lobular breast cancer is uncommon and affects about 1 in 10 of all women with breast cancer. It can occur at any age, but often in the 45-55-year age group. Men can also get invasive lobular breast cancer but this is very rare. Sometimes this cancer is found in both breasts at the same time. There is also a slightly higher risk of it occurring in the other breast at a later date.

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

Triple negative breast cancer: This type does not have receptors (proteins) on the surface of the cancer cells for the hormones, oestrogen, progesterone or HER2. It occurs in about 1 in 5 women with breast cancer and often in younger women.

HER2 positive breast cancer: This means the breast cancer cells have large numbers of the HER2 protein on their surface which can help the cells grow. In these cancers the drug trastuzumab (Herceptin®) can be given.

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

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

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

How is breast cancer graded and staged?

Grading: 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: Staging refers to the size and extent of cancer in your body. For example, if it has spread beyond your breast.

There are various ways to describe staging but the easiest one is by numbers: Stages 1–4. In Stage 1, the cancer is found only in your breast; Stage 2 involves your breast and nearby lymph nodes; in Stage 3, the cancer has spread to more lymph nodes, while in Stage 4, it has spread to other organs in your body.

If you would like to know more about grading or staging, ask your cancer specialist to explain it in more detail to you.



To sum up

- Breast cancer occurs when the cells in your breast tissue grow in an abnormal way.
- Breast cancer is currently the second most common cancer in women in Ireland.
- The cause of breast cancer is unknown. But your gender, age, history of previous breast disease, previous radiotherapy, hormones, family history of cancer and your lifestyle can affect your chances of getting the disease.
- Some symptoms of breast cancer include: a change in size or shape of your breast, changes in the nipple or on and around it, changes in the skin of your breast, swelling in your armpit or around your collarbone, a lump or pain in one part of your breast.
- Breast cancer is diagnosed in a specialist breast clinic.
- Your breast consultant may do a triple assessment: medical history and physical exam; mammogram or X-ray; and a biopsy.
- Breast cancer is divided into two types: ductal carcinoma in situ (DCIS) and invasive breast cancer.
- Grading of breast cancer describes how the breast cancer cells look under the microscope.
- Staging refers to the size and extent of cancer in your body.

Treatment and side-effects

How is breast cancer treated?

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

- The size of the tumour
- The type of breast cancer
- If the tumour has spread to the lymph nodes or other parts of your body.

The lymph nodes in your armpit are of particular importance. Finding out if the cancer has gone to the lymph nodes is important in planning adjuvant (additional) treatment such as hormone therapy or chemotherapy.

In specialist breast units, treatment plans are discussed by your specialists at a team meeting. This includes the surgeon, medical oncologist, radiation oncologist, radiologist, pathologist and breast care nurse. The radiologist reads mammograms and the pathologist looks at cells in the laboratory to diagnose cancer.

Deciding on treatment

Breast cancer can be terrifying at first and feel very urgent. However, most breast cancer patients (regardless of the stage of their breast cancer) can safely take a few weeks to:

- Learn about the good and bad points of each treatment choice
- Make informed choices
- Get a second opinion, if desired.

This time will be well spent. If you are worried that waiting a little will harm your health, ask your doctor if you can spend a week or two thinking about your choices. You may need some time to make informed choices.

What types of treatment are used?

The main treatments for breast cancer are:

- Surgery
- Radiotherapy
- Chemotherapy
- Hormone therapy

They may be used alone, or in combination, to treat breast cancer. Surgery and radiotherapy are referred to as local treatments because they treat only the area where the cancer has occurred. Chemotherapy and hormone therapy are called systemic treatments because they treat your whole body. Your doctor will plan your treatment by considering your age, whether or not you have had the menopause, your general health, the type and size of the tumour, and if it has spread beyond your breast.

Different treatments

You may find that other women at the hospital are having different treatments to you. Try not to worry about this, as you will be given the treatment that is right for you.

Seeking information

If you have any questions about your own treatment, do not be afraid to ask your doctor or breast care nurse. It often helps to make a list of the questions for your doctor and bring a close relative or friend with you to remind you of questions at the time, or of the answers afterwards. If you need advice at any stage, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Some women find it reassuring to have another medical opinion to help them decide about their treatment. If you feel you would like a second opinion, remember you are entitled to ask your GP or cancer specialist to refer you to another specialist.

>>> Make a list of questions for your doctor and bring a close relative or friend with you to remind you at the time.

The breast care nurse

Your breast care nurse may have been involved in your first assessment. She will also be available throughout your diagnosis and treatment.

The breast care nurse is the first point of contact for all your information and emotional support. When you meet your nurse, do ask what is the easiest way to contact her.

Your breast care nurse is also there to give ongoing support and encouragement to you and your family. She will be able to give you information on where any local support groups meet. Also, she can give you information on all aspects of breast cancer and your treatment options.

If you have not yet spoken to or met the breast care nurse, simply call the hospital and ask to speak to them.

Treating cancer that has spread or come back

Sometimes when a woman goes for tests for breast cancer, it has already spread to other parts of her body. This is called secondary or metastatic breast cancer and is not common. Most women have no further problems after their first treatment for breast cancer. But for some women, the breast cancer does come back or spreads to other parts of their body. Before deciding on your treatment, your doctor will consider:

- Which part of your body is affected by secondary cancer cells
- What kind of cancer treatment, if any, you had in the past
- Your general health and your wishes.

For more information, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Understanding Secondary Breast Cancer*.

Surgery

Your surgeon will discuss with you the most suitable type of surgery. Before any operation make sure that you have discussed it fully with your surgeon. Remember, no operation or test will be done without your consent. If a diagnosis of breast cancer has already been made, your surgeon will discuss your operation with you beforehand. The type of surgery you need usually depends on the size of the cancer,

where it is located in your breast, and if there are any more areas of disease in your breast.

There are two main types of surgery:

- Breast-conserving surgery – removal of part of the breast
- Mastectomy – removal of the breast

Breast-conserving surgery

In this type of surgery, only part of your breast is removed. There are different names given to the surgery. For example, lumpectomy, wide local excision, segmental excision or quadrantectomy. The type of surgery you have depends on how much of your breast tissue needs to be removed and where in your breast the cancer is found. All types of breast-conserving surgery will leave some type of scar.

Lumpectomy: This surgery removes only the breast lump and some normal tissue around it. You usually receive radiotherapy some time afterwards.

Wide local excision, segmental excision or quadrantectomy: These kinds of surgery remove more of the breast tissue than in a lumpectomy. You normally receive radiotherapy afterwards.

If cancer cells are found 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, it is said to have a negative or clear margin.

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

Mastectomy

For some women, the best treatment is still a mastectomy (removal of the breast). After a mastectomy, you will be offered a prosthesis (breast form) to wear (see page 26). 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. For some, it can help to regain confidence in their body image after a mastectomy (see page 22).

Bilateral mastectomy

For some women, both breasts may need to be removed. This is called a bilateral mastectomy or double mastectomy. A breast cancer diagnosis can be devastating but more so if you are diagnosed with disease in both breasts. It is natural too that your confidence and self-esteem will be affected. Your surgeon will discuss reconstruction with you. It may also help to talk to a woman who has had bilateral surgery. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, and contact with a Survivors Supporting Survivors volunteer can be arranged.

Choice of surgery

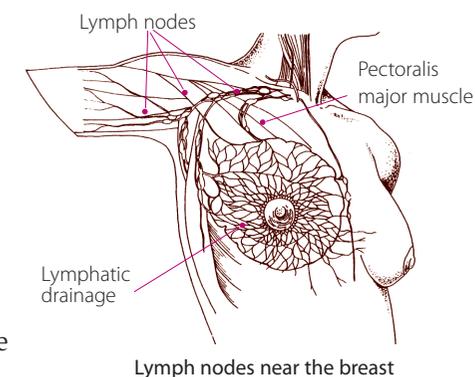
You may be given a choice between breast-conserving surgery and mastectomy. One advantage of breast-conserving surgery is that you keep most of your breast, which will have a scar. A downside is the need for radiotherapy after surgery. But some women who have a mastectomy will still need radiotherapy.

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

Sentinel lymph node biopsy

A sentinel lymph node biopsy is a test to check if cancer cells have reached the lymph nodes. Sentinel means guard and it is thought that there are certain lymph nodes that act as the main draining nodes for the tumour.

When this sentinel lymph node is found, it can be surgically removed and examined instead of removing all the lymph nodes. Sometimes more than one node is removed, for example, two or three. The benefits of this test are that you spend less time in hospital, there is less discomfort experienced



and the risk of lymphoedema (swelling) in your arm is greatly reduced. Sometimes this test is done a few days before the main breast surgery.

During the test: The test involves injecting a small amount of radioactive material into your breast, usually on the morning of the operation. This part of the test is carried out in the X-ray department. The dye follows the path that the tumour cells would take in travelling from the breast through the lymphatic system. A picture is taken at time intervals after the injection. This helps your surgeon to identify the sentinel node. Then at the start of the operation, a blue dye is injected into the breast cancer. Your surgeon then makes a cut underneath your arm. He or she uses a probe to measure areas that have the radioactive dye.

The lymph nodes that have taken up the radioactive dye, or are stained with the blue dye, are removed. Usually one to three nodes are removed. These nodes are sent to the pathologist, who then looks at them under a microscope to see if the sentinel node contains cancer. Your wound is closed, and there may be no need for a drainage tube (drain).

After the test: The sentinel lymph node biopsy can be done together with breast-conserving surgery or a mastectomy. It may take up to 10 days or longer for the pathologist to examine the sentinel nodes and give the final results. This is because it can take about 24–48 hours for the radioactivity of the lymph nodes to fade before they can be examined. If the sentinel lymph node is clear of tumour cells, it usually means that the other lymph nodes are clear. But if the sentinel lymph node is not clear of tumour cells, then further surgery to the lymph nodes may be needed. Your doctor will discuss this with you.

Lymph node removal

If the lymph nodes from your armpit are tested and show cancer cells, some more nodes will be removed. In some cases, all the lymph nodes in your armpit may 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 waste fluids for a few days. The drain is removed when there is hardly any fluid flowing out.

You will also need to do special arm exercises as shown by the hospital physiotherapist. There is a small risk of swelling in your arm (lymphoedema). This can happen any time after the operation. But there are ways to reduce the risk of this happening to you (see pages 24 and 25). The area under your arm will feel numb or sore for a while and you may experience some tingling or pins and needles. You may also experience some discomfort, but you will receive regular painkillers to help with this.

After your breast surgery

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

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

After an axillary clearance, your stay is usually longer. It can depend on the amount of fluid in your drains. Some hospitals allow patients to go home with their drains in and, if so, you will be shown how to empty them. After a sentinel lymph node biopsy, your hospital stay will be shorter.

Side-effects of surgery

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

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

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

Fluid under wound: After the drains have been removed, you may experience a collection of fluid under the wound. Do not be alarmed if this occurs. It is called a seroma and can feel like a lump. Tell your doctor or breast care nurse, who may drain the fluid with a needle. This normally only takes a few minutes and is not usually uncomfortable.

Leaving hospital

Before you leave hospital you will be given an appointment for a check-up at the outpatient clinic. This visit will be a good time to discuss any problems you have after your operation.

When you get home, do 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. The hospital dietitian can give you advice if you wish. You will probably be advised not to lift or carry anything heavy nor to 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 and match the remaining natural breast as closely as possible. This can either be done by creating a breast 'form' with an implant that is placed beneath the skin and muscle that covers your chest, or by using skin, fat and muscle from another part of your body. A combination of these techniques is used for some women. Sometimes this can be done at the same time as the mastectomy, but often it is done some months or even years after the original operation. You may have a number of choices if you decide to have reconstructive surgery, though one type of operation may be more suitable than another.

If you would like to consider breast reconstruction, discuss it with your doctor before surgery. He or she can tell you about the different

methods available or refer you to a plastic surgeon. Further information is available from the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Understanding Breast Reconstruction*.

Why have a breast reconstruction?

Some women find it harder than others to accept the idea of losing one or both of their breasts. It is natural to feel distressed, and every woman has the right to do something about their loss. Some women may feel guilty for thinking about reconstruction and that it might even seem vain. This is not so – reconstruction can be an important part of treatment that helps emotional recovery and well-being.

Where can I have breast reconstruction?

Your breast reconstruction should be done by either a specialist plastic surgeon or a breast surgeon who has special training in some or all reconstructive techniques. Breast cancer surgeons do not usually carry out the more complex types of breast reconstruction. Before you decide to go ahead with your operation, you need to be sure that your surgeon has answered all your questions to your satisfaction. If you would like to discuss your reconstruction options with more than one specialist, your GP or surgeon may be able to recommend someone else.

Questions to ask your surgeon about breast reconstruction



- What type of surgery would you recommend for me? Why?
- What are the risks and benefits associated with this type of surgery?
- What is your experience in this type of surgery?
- What can I expect my reconstructed breast to look and feel like? Immediately after surgery? After 6 months? After 1 year?
- Can I see some reconstruction photographs?
- How long will I need to stay in hospital?
- How long will it take me to recover?
- What do I need to do to ensure a good recovery?

Lymphoedema

If your surgeon has removed some lymph nodes from under your arm, you may be at risk of a condition called lymphoedema. This is a swelling caused by a build-up of lymph fluid in the tissues of your arm on your operation side. This build-up is due to the effects of surgery or radiotherapy to the lymph nodes in your armpit and nearby areas. Lymphoedema can occur immediately after surgery or radiotherapy or can develop later, sometimes many years after treatment.

After having lymph nodes removed, your hand and arm will be more at risk of infection. Even a small cut or burn or graze can sometimes become infected. Take care of your hand and arm on the operation side, particularly when gardening or when using sharp knives. Always wear rubber gloves when washing up and use oven gloves when cooking. Make sure the skin on your arm is kept clean, dry and moisturised. Avoid sunburn or bites.

If you do get any sign of swelling, pain, inflammation or tenderness, get your doctor's advice as soon as possible. You may need antibiotics to prevent the infection from getting worse and perhaps causing lymphoedema. If you also start to feel flu-like, contact your doctor immediately. See page 25 for a list of dos and don'ts about lymphoedema prevention and care.

You should also avoid putting strain on the arm where the lymph nodes have been removed. For example, lifting heavy loads or moving furniture. But continue to use the arm normally and do exercises to encourage lymph flow through the arm.

If you do develop a swelling of your arm, which may be lymphoedema, contact your breast care nurse or oncologist. Your oncologist can refer you to a lymphoedema therapist who can treat the condition. This may involve specific hosiery (sleeve for arm), special exercises and types of massage.

For more information or a factsheet about arm lymphoedema, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



Dos and don'ts on lymphoedema prevention and care



Dos

- 1 Do use your at-risk arm normally, as using the muscles will help to improve lymphatic flow.
- 2 Do build up your strength and stamina with keep-fit activities, the use of weights and aerobic exercises. These should be gradually introduced and guided by an instructor.
- 3 Do eat a well-balanced diet and keep your weight within normal limits.
- 4 Do keep your hand and arm clean and dry and moisturise your skin often.
- 5 Do wear rubber gloves when washing dishes or clothes or while gardening. Wear oven gloves when handling hot foods.
- 6 Do treat any cuts and sores by washing them with soap and water and putting on antiseptic cream and a plaster.
- 7 Do protect your arm from sunburn and insect bites. Use a sunscreen with at least a sun protection factor of 15 (SPF 15) and use an insect repellent that is non-drying on your skin.
- 8 Do use an electric razor when shaving your armpit.

Don'ts

- 1 Don't expose your body to extreme temperatures. For example, very hot baths or very cold showers. This includes saunas and steam rooms or heated compresses on the affected side.
- 2 Don't do any activity that puts a heavy strain on your at-risk arm. This includes moving furniture, picking up or carrying heavy weights (like children or shopping) or working at heavy tasks and DIY activities.
- 3 Don't wear jewellery, a watch or tight-fitting clothes on your upper body, as it may restrict blood flow on your affected hand or arm.
- 4 Don't get manicures that cut or damage the skin around your nails.
- 5 Don't allow your affected arm to be used for tests. Offer your other arm instead for measuring blood pressure, taking blood samples, getting injections, acupuncture or vaccinations.

Breast prostheses

A breast prosthesis is an artificial breast form which fits into a bra cup to replace your natural breast after a mastectomy. After surgery, you will not be able to wear anything that puts pressure

on your scar and the surrounding area for 6–8 weeks. While your scar is healing, your breast care nurse will be able to give you a lightweight temporary prosthesis. This is made of synthetic washable fibre. It can be worn immediately after surgery, and will help maintain your outward appearance during the initial period after your operation. Some women find that a bra is too constricting during this time. If you prefer, you can wear a camisole top or a cotton vest with Lycra to give you support.

Later (usually after about 6 to 8 weeks) you can be fitted with a permanent breast prosthesis. This is made from silicone gel moulded to form the natural shape of a woman's breast. It resembles the movement, feel and weight of normal breast tissue. There is a wide range of prostheses available in different shapes, sizes and skin colours. A properly weighted prosthesis will provide the balance your body needs for correct posture.

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 the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or see our factsheet, *Breast Prostheses*.

After breast cancer surgery, you are entitled to your first permanent prosthesis and two bras free of charge.

Radiotherapy

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



Prosthesis shapes

Radiotherapy can be given for different reasons. It is often given after breast surgery, especially a lumpectomy, or chemotherapy, as part of adjuvant therapy. This is done to reduce the risk of the cancer coming back. It can also be given to help shrink a large tumour. If the cancer has spread and is causing pain or pressure, a small dose of radiotherapy can relieve pressure by reducing the tumour in size.

Radiotherapy to the breast can be given externally or internally. When given externally, it is called external beam radiation. When given internally, it is called brachytherapy. External radiotherapy is the most common way to give treatment.

With external beam radiotherapy, the radiation comes from a special machine called a linear accelerator. This aims the X-rays directly at the tumour or to the breast tumour site after surgery. Radiotherapy is always given to women who have had part of their breast removed and sometimes to women who have had a mastectomy.

Brachytherapy or interstitial radiotherapy is a form of internal radiotherapy. If this type of radiotherapy is suitable for you, your radiation oncologist will give you more information about it.

Planning your treatment

Before radiotherapy, your doctors and other specialists plan how to give it to you. They work out how to give you the right amount of radiotherapy with the least damage to normal cells. On your first visit to the radiotherapy department, you may be asked to lie under a simulator or CT scanner that takes X-rays of the area to be treated. The simulator or CT scan can take up to an hour to complete the measurements. Treatment planning is a very important part of radiotherapy and it may take a few visits before your treatment can go ahead.

You will have marks put on the skin where you are to be treated. This may be with ink or a tiny permanent tattoo. This is so the rays can be aimed at the same area each day. The ink marks are temporary and should not be washed off until treatment is over.

Before starting radiotherapy you will be told how to look after your skin during and after treatment.

Getting your radiotherapy

Radiotherapy treatment is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your treatment can go on for several weeks (5–6 weeks). Each treatment session only lasts a few minutes. It will not cause you any pain during treatment but you will be asked to lie still. How much you need will depend on the type and size of the tumour. Your doctors will discuss this with you.



Linear accelerator

Each time you go for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie or sit in a certain position under the machine. When you are ready he or she will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist will be able to see you all the time through a closed circuit camera. You can talk through an intercom to the radiography staff if you need to. External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

Will I have any side-effects?

Radiotherapy is given directly to the site of the cancer. Therefore, most of the side-effects that occur are related to the part of your body being treated. How severe these side-effects are will vary from person to person, depending on the amount of treatment received.

When the breast/chest wall is being treated, the most common side-effects are:

- Skin changes
- Tiredness (fatigue)
- Indigestion

Skin changes: During radiotherapy the skin in the treated area may become red and sore. It may look like sunburn. A special cream can be used to treat this problem. Only use creams recommended to you

by the nurses or radiation therapists. If you need to wash the area use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin. Clothing covering the treatment area should be loose fitting and made of natural fibres. Tight-fitting bras should be avoided. As treatment continues it may be helpful to wear a crop top or vest next to the skin. When receiving radiotherapy the treatment area should not be exposed to full sunlight. After treatment is completed, the area should not be exposed to sunlight until completely healed. Even after several months you should use a very high factor sunscreen. The skin will stay sensitive to sun for at least a year after treatment.

Tiredness (fatigue): This can build up over the course of your treatment. It may be due to the treatment itself or maybe you have to travel long distances to come for treatment. Sometimes your blood count, in particular haemoglobin (the iron part of your blood), can drop. This can also make you feel tired. Your radiotherapy doctor will keep an eye on this. Rest as much as you can. Cut down on the things you normally do while you are having treatment. If you would like more information on tiredness, contact the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Coping with Fatigue*.

Indigestion: This can occur if the area being treated is close to your food pipe (oesophagus). Your breast care nurse will advise you on possible treatments. If you would like more information on indigestion, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Diet and Cancer: A Guide for Patients with Cancer*.

These or any other effects you develop will be watched very carefully during the radiation treatments. Information will be given on how to prevent side-effects and medication will be prescribed if needed. All these side-effects should go away when treatment is over, but do let your doctor know if they continue.

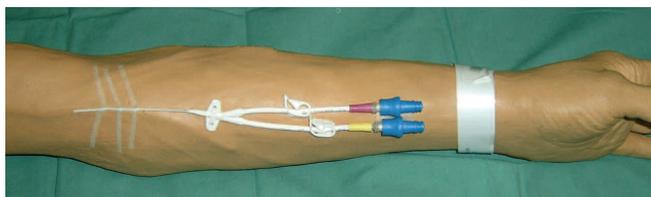
Further information on radiotherapy is available through the National Cancer Helpline on 1800 800 200 700.

Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. It is one of the main types of drug treatment used for breast cancer.

The drugs might be given before or after surgery. They can help to make the tumour smaller when given before surgery (neoadjuvant treatment). They can help prevent cancer spreading or coming back when given after surgery (adjuvant treatment). And they can also be given to treat cancer that has spread or come back. These drugs can be used on their own or in combination with each other.

The drugs used in chemotherapy travel through your bloodstream to almost every part of your body. They are often given in cycles such as once every 2 or 3 weeks with a rest period between treatments. Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.



PICC line giving chemotherapy into an arm vein

There are several chemotherapy drugs used to treat breast cancer. Your doctor or breast care nurse will discuss your treatment with you. A number of chemotherapy drugs are often used together. Treatment time varies from 4 to 6 months. Sometimes it may be slightly shorter or longer than this period. The rest period between treatments allows your body time to recover from the side-effects of treatment.

For more information on different types of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Oncotype DX® test



The Oncotype DX® test looks at your breast cancer tissue under the microscope. It can help predict how your cancer will respond to treatment. This information can then help your cancer specialist to plan your treatment. For example, if you need chemotherapy or not. The Oncotype DX® test can be used if your breast cancer is early stage, node negative, and oestrogen-receptor-positive (ER+). The test looks at the activity of 21 genes in your breast cancer once it has been removed. These genes are measured and a figure is calculated, which is your breast cancer recurrence score.

The recurrence score tells how likely it is that your breast cancer will return. A low score indicates a lower risk, while a high score indicates a higher risk. Your cancer specialist will advise you if you are suitable for the test and explain the relevance of your score. If you have a high recurrence score, you will be advised to have chemotherapy as well as hormone therapy.

Side-effects of treatment

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both healthy cells and cancer cells. In most cases the side-effects go away when the treatment ends or soon after. You will be given special medications to help you cope with the side-effects.

Side-effects may include:

- Nausea and vomiting
- Infection
- Anaemia
- Bruising
- Sore mouth
- Hair loss (alopecia)
- Constipation and diarrhoea
- Fatigue
- Skin and nail changes

Nausea and vomiting: Some chemotherapy drugs make you feel sick (nausea) or get sick (vomit), but many people experience no sickness at all. When it occurs will depend on the drugs given. It can vary from soon after to several hours or even several days after chemotherapy injections.

If you are receiving a drug that can cause sickness, your doctor will prescribe medications to prevent it. These are called anti-emetics. You may receive them immediately before your treatment and in tablet form for when you go home. The aim of the anti-emetics is to prevent any nausea and vomiting so if you do experience any nausea or vomiting it is important to tell your doctor. Some anti-emetics work well for some people and not for others, and your doctor will be able to prescribe another one for you. You may need a combination of anti-emetics to help prevent any nausea and vomiting.

If you are unsure how to manage nausea, contact the oncology nurse for advice. He or she will give you telephone numbers to call if you have problems due to chemotherapy, day or night.

>>> Hints & Tips – nausea

- Eat small amounts of food regularly.
- Avoid fatty foods.
- Avoid foods that make you feel sick.
- Avoid taking a lot of fluid just before you eat.
- Try food or drinks containing ginger or peppermint.
- Take plenty of fluids in small amounts throughout the day.



Infection: Chemotherapy can affect your bone marrow, which is responsible for making blood cells. White blood cells fight infection and when these are low in your body (neutropenia) you are more prone to picking up infections. While on chemotherapy it is important to avoid children and adults who have colds or other infections, such as chickenpox, shingles or measles. You should contact your doctor if you have a sore throat, cough, pain passing urine, redness or swelling or have a temperature of 38°C or higher. You should take extra care with your personal hygiene, making sure you wash your hands well after using the bathroom. Eat a well-balanced diet, wash foods thoroughly and avoid fast food or takeaway food. You will have regular blood tests to measure your number of white blood cells. Sometimes your doctor will prescribe a white blood cell growth factor called GCSF, which is given as an injection under your skin.

>>> If you are feeling shivery and unwell or running a high temperature of 38°C or higher, tell your doctor straight away.

For more information on food precautions, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Diet and Cancer*.

Anaemia: Anaemia occurs when the red blood cells that carry oxygen around your body are reduced. You may feel very tired, breathless, dizzy and light-headed. You will have regular blood tests to measure your red blood cell count (haemoglobin). You may need a blood transfusion or your doctor may prescribe an injection called erythropoietin to make more red blood cells.

Bruising: Platelets are other blood cells that are made in your bone marrow. They help to stop bleeding by clotting the blood. If your platelet count is low (thrombocytopenia), you will be more prone to bruising and bleeding. Let your doctor know if you have unusual or prolonged bleeding or if you notice a pinpoint-like rash on your body. Your platelet count will be measured regularly and you may need a platelet transfusion.

Sore mouth: The cells lining your mouth can be affected by chemotherapy, causing a sore mouth. It is important to take special care of your mouth. Your doctor will prescribe mouthwashes, which should be used regularly. You should use a soft toothbrush, remove and clean dentures regularly and drink plenty of fluids to keep your mouth moist. Keep your lips moist by applying Vaseline and avoid very hot or acidic drinks. If you develop an ulcer, let your doctor know, as these can become infected. Chemotherapy can also cause your sense of taste to change. This will improve after your treatment has finished.

>>> Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection.

Hair loss (alopecia): Not all chemotherapy drugs cause hair loss. Some may thin your hair while others do not affect it at all. You may lose all body hair including your eyelashes and pubic hair, which can

be very distressing. Your doctor or nurse will let you know if the chemotherapy you are receiving causes hair loss. Your hair can begin to fall out within a few weeks of your first treatment and will begin to grow back a few weeks after your last treatment.

It is important to pick out a wig before your hair falls out, as this will help you to match your usual style. Some people find it helps to cut their hair very short before it falls out and to wear a hairnet at night. This is because it can be very upsetting to wake up in the morning with a lot of hair on your pillow. Not everyone will want a wig and there are other alternatives like scarves, caps and turbans. It is important not to use chemical hair dyes or to perm your hair while you are on treatment. Avoid using hair dryers, curling tongs and curlers. Pat your hair gently after washing and use a soft or baby brush. If you find hair loss extremely distressing, there is a way to reduce the amount of hair loss. This is called scalp cooling. It works by cooling your head and reducing the blood flow to your scalp. This reduces the amount of drug reaching your hair follicles. This treatment is not suitable for everyone. It can only be given in certain circumstances and is not available in every hospital. You can ask your doctor or nurse about scalp cooling.

Constipation and diarrhoea: Chemotherapy can also cause a change in your bowel habits. Some drugs may cause diarrhoea. Passing watery bowel motions more than twice a day is known as diarrhoea. If you have diarrhoea you should drink plenty of fluids, avoid a high-fibre diet and contact your doctor if it persists. There are medications that can be taken to relieve this symptom.

Chemotherapy may also slow down the movement of your bowel, making it difficult to pass a bowel motion. This is called constipation. If you get constipated, drink plenty of fluids and eat a high-fibre diet. Tell your doctor if it persists as you may need medication to help relieve it. For example, laxatives.

Fatigue: Fatigue is extreme tiredness. It may be due to the cancer or to symptoms caused by the cancer. It can also be a side-effect of treatment. Fatigue can affect you physically and emotionally. It can be very frustrating, as it may not go away with rest. Fatigue can remain for up to 6 months after your treatment has finished. See page 46 for ways to manage your fatigue.

Skin and nail changes: Some drugs can affect your skin. For example, it can become dry or discoloured. Any rashes should be reported to your doctor. Chemotherapy also makes your skin more sensitive to sunlight. You should protect your skin at all times from the sun by wearing a hat, a long-sleeved shirt and by using a skin protection factor sunscreen (SPF) of at least 15 with a UVA rating of 4–5 stars. You should also avoid the sun between the hours of 11am and 3pm.

Your nails may grow more slowly and become more brittle and flaky. Sometimes the shape and colour of your nails may change.

Other changes: Some chemotherapy drugs can cause damage to your kidneys. To prevent this, fluids may be given to you before and after your treatment. It is also important to drink as many fluids as possible while at home. Try to drink about one and a half litres per day.

Some drugs can also affect your nerve endings. They may cause numbness, tingling or a burning sensation in your hands and feet. This is known as peripheral neuropathy. This side-effect is almost always temporary and goes away after treatment stops, but it can take several months to go away completely. Tell your doctor if you experience these symptoms. He or she may give you medications to help, or your treatments may need to be changed slightly.

Some chemotherapy drugs can cause a continuous sound (buzzing or ringing) in your ears. This is called tinnitus. Do tell your doctor if you develop this problem.

For the effects of chemotherapy on your fertility, see page 44.



To sum up

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

Biological therapies

Biological therapies are also known as targeted therapies. They use your body's immune system to fight cancer and other diseases. Most targeted therapies work like the antibodies made by your immune system. These drugs target specific features of cancer cells. For example, a protein, an enzyme or new blood vessels. Unlike chemotherapy, targeted therapies do not harm healthy cells.

Targeted therapies used in the treatment of breast cancer include:

Trastuzumab (Herceptin®): Trastuzumab is a monoclonal antibody used to treat breast cancer or secondary breast cancer. Some breast cancer cells divide and grow when a protein called human epidermal growth factor attaches itself to another protein known as HER2. HER2 is a receptor found on the surface of some breast cancer cells. Trastuzumab works by interrupting the way HER2 positive breast cancers grow. The drug attaches to the cancer cells, stopping the growth factor attaching to the HER2 protein. This causes it to slow down or stop the cell from growing. Trastuzumab is given into a vein through a drip.

You will only receive the drug if your breast cancer is HER2 positive. This means the breast cancer has too much of the protein called HER2. About 1 in 5 female breast cancers are HER2 positive. This type tends to grow faster than HER2 negative cancers. Your cancer tissue will be routinely tested for HER2.

Lapatinib (Tyverb®): Lapatinib is usually given for secondary breast cancer and if you have HER2 positive breast cancer. Some cancer cells have special proteins on their surface called growth factor receptors. When turned on, these proteins turn on another protein called kinase inside the cell and cause the cancer cell to grow.

Lapatinib is known as a kinase inhibitor and works by stopping the growth factor receptor. It then stops the kinase from working and prevents the cancer cell from growing. Lapatinib targets the growth factor receptors called ERB-1 and ERB-2. Your doctor may also refer to these as EGFR epidermal growth factor receptor and HER2.

Lapatinib is usually given within a clinical trial. It is often given along with a chemotherapy drug called capecitabine (Xeloda®). Lapatinib is

taken as a tablet. There are also clinical trials looking at using lapatinib to treat primary breast cancer.

Bevacizumab (Avastin®): Bevacizumab is another monoclonal antibody. It may be used to treat secondary breast cancer and other cancers. Cancer cells need a blood supply to receive food and oxygen and so allow them to survive and grow. A protein called vascular endothelial growth factor (VEGF) helps cancers to grow these blood vessels.

Bevacizumab works by preventing blood vessels being formed. As a result, the cancer is starved and cannot thrive. Drugs that prevent blood vessels forming are known as angiogenesis inhibitors. Bevacizumab also improves the effects of chemotherapy. It is given through a drip.

For more information on targeted therapies, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Hormone therapy

Hormone therapy is a treatment using hormones that can kill cancer cells, make them grow more slowly or stop them from growing. Hormones are substances that occur naturally in your body. Female hormones include oestrogen and progesterone. Hormone therapy is one of the main types of drug treatment used for breast cancer and might be given before or after surgery. It can help to make the tumour smaller when given before surgery (neoadjuvant treatment). Usually it is given after surgery (adjuvant treatment) to help prevent cancer spreading or coming back.

You might receive hormone therapy if your breast cancer is hormone-receptor positive. This means that your cancer cells have receptors on their surface that latch onto the female hormone oestrogen. This causes the cancer cell to grow. Oestrogen-receptor positive cancers are common.

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

A tissue sample of your cancer cells will be tested for hormone receptors. This sample is taken during a biopsy or after surgery to remove the breast cancer.

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

For more information on hormone therapies or for factsheets on hormone treatments call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or see our website, www.cancer.ie.

Types of hormone treatment

Tamoxifen: Tamoxifen is a commonly used hormone treatment. It works by blocking the uptake of oestrogen by the receptor on cancer cells. Tamoxifen is usually given in tablet form, once a day.

Aromatase inhibitors: These are a group of drugs that block the making of oestrogen in women who have had the menopause. They work by blocking hormones called androgens that are changed into oestrogen by an enzyme known as aromatase. Examples of drugs in this group are anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®). These are usually given in tablet form, once or twice a day.

LHRH analogues: Luteinising hormone-releasing hormone (LHRH) analogues are drugs which are given to premenopausal women and are injected under your skin. These drugs change the levels of hormones released in your brain that control how your ovaries work. This stops the ovaries making oestrogen. 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®).

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:

- Periods may stop
- Osteoporosis
- Thickened womb
- Bone loss and pain

No periods: For younger women who are still having periods, hormone treatment may cause periods to stop. The physical effects of this may include hot flushes, night sweats, dry skin and dryness of your vagina. These can make sex uncomfortable and cause a decrease in sexual desire. If you have had the menopause, you are also likely to experience similar side-effects, particularly if you have recently stopped hormone replacement therapy.

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. It happens particularly if LHRH analogues are given. Discuss with your doctor or nurse how it can be prevented.

Tamoxifen may have a beneficial effect on bones, by preserving bone density (thickness) after the menopause. It is also good for reducing cholesterol, but can cause increased blood clotting (thrombosis). The risk of blood clots is about 1.5 in 100 women.

Thickened womb: Tamoxifen can cause the lining of your womb (uterus) to become thickened. There is a small risk of developing cancer of the womb while on tamoxifen. The risk is about 1.7 in 1000 women. For this reason, you should report any vaginal bleeding to your doctor while you are on tamoxifen.

Bone loss and pain: Aromatase inhibitors may increase bone loss and cause pains and aches in your muscle or bone joints. For this reason, bone density scans may be done as a baseline (before starting treatment) and regularly while on this treatment. You should also stop smoking, take regular exercise and take calcium in your diet. Ask your doctor about taking calcium supplements. Drugs may be prescribed if there is serious bone loss (osteopaenia).

There are other ways to lessen the side-effects of hormone treatments. Ask your doctor or nurse what side-effects you can expect and how to manage them. Also, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil for the factsheet *Understanding and Managing Menopausal Symptoms*.

Women after the menopause (postmenopausal)

In the past, postmenopausal women with breast cancer that is oestrogen-receptor (ER) positive have usually taken tamoxifen for 5 years. However, recent studies have shown that either replacing tamoxifen with an aromatase inhibitor or switching to an aromatase inhibitor for 3 years, after 2 years of taking tamoxifen, may be better at preventing breast cancer from returning. Your doctor will discuss with you the best hormone treatment for you. Other studies are looking at the possible benefits of taking hormone therapy for longer than 5 years. You may be asked if you would like to take part in such a study. For more about clinical trials, see page 49.

Women before the menopause (premenopausal)

Studies have shown that reducing the levels of oestrogen in your body can be a useful treatment if you have not gone through the menopause (premenopausal). Tamoxifen is recommended if your cancer is oestrogen-receptor positive. It is usually advised to take it for 5 years, although research suggests that some women may benefit from taking it for up to 10 years. Your doctor will discuss what is right for you.

But you may also receive a course of chemotherapy usually before tamoxifen. Chemotherapy may bring on an early menopause by stopping your ovaries from working normally and stopping your periods. This may also reduce oestrogen levels.

In some women, periods may return after chemotherapy treatment and despite being on tamoxifen. If this happens, your specialist may prefer to keep oestrogen levels low by stopping your ovaries from working. There are three ways to stop your ovaries working:

1 Drug treatment: Certain drugs known as LHRH analogues (for example, goserelin) can switch off your ovaries. This has the same effect as surgery or radiotherapy but is usually reversible. This means that when drug treatment is stopped, your periods may return and the side-effects may reduce. As a result, your doctor might suggest drug treatment instead of radiotherapy or surgery.

2 Surgery: This is where your ovaries are removed. It is usually advised if you have a breast cancer diagnosis and the genes for breast and ovarian cancer (BRCA 1 and BRCA 2).

3 Radiotherapy: This permanently stops your ovaries working but is not often done.

Breast cancer that has spread or returned

All the hormone treatments described above may be used as treatment for secondary breast cancer, particularly if the cancer has spread to bones. The type of hormone treatment will depend on if you are premenopausal, postmenopausal and if other hormone treatments have already been used.

For more information on secondary breast cancer and hormone treatments, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Soy and hormone therapy

Many believe that soy products can help protect against some types of cancer because of the high amount of isoflavones found in them. Isoflavones are compounds very like the hormone oestrogen. So far there is no clear evidence from research that soy can reduce your cancer risk. Until the issue becomes clearer, many doctors advise that you should avoid soy supplements if you are taking hormone therapy for oestrogen-receptor-positive breast cancer.

In general, soy is a good source of protein and low in saturated fat. It is fine to eat moderate amounts as part of a balanced diet. But if you are taking hormone therapy for breast cancer, and you are concerned about isoflavones, ask your doctor or dietitian about how much you can eat safely. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet called *Diet and Cancer*.

Will treatment affect my sex life?

You may find that your sex life changes during and after your treatment. This can make you feel insecure about your sexuality and your relationship with your partner. But remember that not everyone will experience problems. There is no medical reason to stop having sex while on treatment unless your doctor advises against it. But do use a reliable method of contraception throughout your treatment and for some time afterwards. See page 44 for more about contraception.

Physical effects

Different treatments may affect you in different ways. For example, surgery may alter your body image and cause you to be embarrassed in front of your partner. 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. A premature menopause and infertility may also affect your sexuality and these are often linked to sexual problems. Any of the above changes may make you feel less feminine.

Sexuality

Breast cancer surgery can be a deeply traumatic experience. You may feel that your breasts are very important to your idea of yourself as a woman. You may also find that your changed body appearance severely affects your self-confidence and makes you feel vulnerable.

The first months are likely to be very upsetting and many women are full of conflicting emotions. These can include grief, fear, shock, anger and resentment mixed perhaps with relief that the cancer has been found and treated.

Strong emotions may affect your sexual feelings for a while. Fear that your partner – even a longstanding one – may be put off by the result of the surgery can make you anxious about allowing someone to see or touch your body.

If you are single, it may be daunting starting a new relationship. You may worry about when to tell your new partner about your breast cancer. But as you spend time and feel more comfortable together, your trust will increase and you will know when the time feels right.

Ways to help

You and your partner will naturally need time to accept any changes resulting from a cancer diagnosis. It may take a while to get the balance back in your sexual relationship. Talking to one another can help a lot but remember there is also professional support available.

Women find different ways of trying to come to terms with the change to their bodies. You might need time simply to be alone, to try to comfort yourself and build up the courage to face someone else – even a deeply loved partner. Or you might need almost immediate physical comfort and find loving touch a powerful relief to the fear of rejection.

Letting someone else see your new appearance can be the first step in coming to terms with your situation. You might prefer to see the results of your surgery for the first time alone. Or you might want the support of a partner, close friend, doctor or nurse when you take your first look.

Gradually your wound will heal and your scars become less obvious. As you get used to the soft breast prosthesis, it should also help to restore your confidence.

Who can help?

Help is available right throughout your treatment and at any time afterwards. You can talk to your breast care nurse or medical social worker. Your doctor might suggest you visit a counsellor or sex therapist, if you think that would be helpful.

If you would like more advice and support, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, where you can speak to one of our specially trained nurses or ask for a copy of our factsheet, *Breast Cancer and Sexuality*.

Will treatment affect my fertility?

Your treatment will raise issues such as contraception, pregnancy and fertility.

Contraception

It is important not to become pregnant while on chemotherapy or hormone therapy. Even if your periods stop while on treatment, you will still need to use contraception if you are sexually active. As the cancer may be affected by hormones, you are advised not to take the contraceptive pill.

Barrier methods of contraception such as condoms or the cap are suitable. Lubricating jelly like K-Y® Jelly is safe to use with barrier contraceptives if extra moisture is needed during sex.

Your hospital doctor or GP can give you good contraceptive advice. He or she can also fit you for a cap if this is the contraceptive you choose. Family planning or Well Woman clinics will also advise you on contraception. Coils (IUDs) are effective, but not the types that use the female hormone progesterone. Again, your GP can fit you with a coil if you wish. Some women choose to be sterilised to prevent the risk of pregnancy.

The choice of contraceptive is largely a personal one. Your likes and dislikes, and those of your partner, if you have one, are important. You may also have religious and moral beliefs to consider. Remember the withdrawal and rhythm methods of contraception are not safe enough as protection against pregnancy in this case. You may find that discussing your situation with your religious leader or a trained counsellor helps you find an acceptable alternative.

Pregnancy

Pregnancy should be avoided during chemotherapy in case the drugs harm your baby. Many doctors advise not getting pregnant for 2 years after your chemotherapy ends. There can also be a risk of miscarriage or birth defects in children. You should speak to your doctor if you have any worries.

If you become pregnant before your cancer is diagnosed, it is important to discuss all your options with your doctor. Your options will depend on both the stage of your pregnancy and the stage of your disease. In some cases, it is possible to have chemotherapy or surgery and deliver a healthy baby too.

Hormone replacement therapy (HRT)

If you have had breast cancer, you are usually advised not to take hormone replacement therapy. This is because it contains oestrogen and may cause the cancer to recur.

Fertility

Some drugs used to treat cancer have no effect on your fertility, while other drugs can affect your ovaries. Your periods may become irregular or stop during treatment or for a few months afterwards. You may get some symptoms of the menopause like hot flushes. But your periods may return to normal after a few months. 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 more likely chemotherapy is to stop your periods permanently. When you are finished treatment, blood tests can check if you are fertile or not.

If there is a risk that your chemotherapy will cause long-term infertility, you may have the option of freezing your eggs before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin provides a service where eggs can be frozen. You must be referred there by your oncologist, be over 18 and give an informed consent. Remember you may not be suitable for it, so you should talk to your oncologist before you start your treatment.

Coping with infertility

Depending on your age, you may feel devastated if you are told you can no longer have children. It can take a while to sort out your emotions and be able to talk about them. It may be helpful to talk to your partner or a friend about how you are feeling. But you do not have to cope with these feelings alone. There are many support groups and counsellors

available to help you. Ask your breast care nurse or call the National Cancer Helpline on 1800 200 700 for more details or visit a Daffodil Centre.

How can I cope with fatigue?

Fatigue is a common symptom of cancer and is often described as an overwhelming tiredness. You may also find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It may be caused by worry when a diagnosis of cancer is made or the added stress caused by treatment.

Even though you may find it hard to identify the reasons for your tiredness, there are still ways to improve it. For example, your cancer treatment may help to relieve symptoms such as pain and nausea. This can allow you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

Eating a well-balanced diet is also important. Keep a fatigue diary so you can see when your energy levels are highest. That way, you can plan your work for this time. If you are feeling very worried and find it hard to sleep at night, tell your doctor or nurse. He or she can give advice. Try talking to your close family or friends about your concerns too. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to take part in physical exercise, try to do some regularly. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

Tell your doctor or nurse about your fatigue as they can help with some symptoms. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Coping with Fatigue*. It also contains a fatigue diary.

➤➤➤ Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping.

What follow-up do I need?

After your treatment, you will have regular check-up visits with your specialist. This is called follow-up. At first these visits will be quite often but then become less frequent. They will include a physical exam and a routine mammogram once a year. Your doctor will check for signs of recurrence of the cancer or follow up on any side-effects you still have. He or she can also check for signs of new effects that may develop after you have finished your treatment.

In rare cases, some types of chemotherapy may cause long-term damage to your heart and lungs. There is also a slight risk of developing a second cancer because of your treatment. If you are between check-ups and have a symptom or problem that worries you, let your specialist know and visit him or her as soon as possible.

The visits to your specialist and yearly mammograms may continue for a number of years. That said, each patient is different and it may be possible for your GP to take over your care after a shorter time. Ask your specialist about how long your follow-up will continue.

Life after treatment

It can take at least a year for you to get over the effects of treatment. Do not be in a rush to get back to your normal routine with work, just do as much as you are comfortable with. Remember you may feel very anxious after treatment. You might miss the regular contact with the hospital staff or worry about the cancer coming back. If you feel you might need help coping, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can speak to a specialist nurse, who can advise you about counselling in your area.

Exercise after a cancer diagnosis

Surviving cancer and making it through treatment are big achievements. Research has shown that exercising after a breast cancer diagnosis can help reduce the risk of your cancer coming back. Exercising can also help you feel better and improve your overall quality of life.

How much do I need?: Exercising at a moderate rate for 2-3 hours a week can help reduce your risk of a breast cancer recurrence. Moderate exercise is when you are doing an activity that increases your breathing and heart rate and you become warm or sweat slightly. The pace is comfortable and are still able to hold a conversation. Do check with your doctor or GP first before starting exercise. Discuss any other conditions you have, such as high blood pressure, diabetes or lung problems, as these may be affected by exercise.



Research – what is a clinical trial?



Research into new ways of treating breast cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully watched during and after the study. You might also receive a treatment that later proves to be better than the current best standard treatment.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends.

If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

If you would like more information, a factsheet on clinical trials is available. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy.

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies:

Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Nutrition therapy
- Relaxation
- Music, art and dance therapy
- Visualisation
- Shiatsu
- Gentle massage
- Yoga
- Aromatherapy
- Acupuncture
- Reflexology
- Hypnotherapy

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include:

- Diet therapy
- Megavitamin therapy
- Herbalism

Most doctors do not believe that such treatments can cure or control cancer. Diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.



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



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Make sure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

Common reactions include:

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

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer*. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy.

Shock and disbelief

'It can't be me.'
'Has there been a mistake?'
'Cancer happens to other people, not me.'

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss your cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you don't really believe what is happening to you.

Fear and uncertainty

'Am I going to die?'
'Will I be in pain?'
'Will I become a different person?'

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers can be cured or controlled with modern treatments.

Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers. You may also have fears that your experience of cancer will change who you are and that people will reject or avoid you. For example, after surgery your body image may be different, and it will take some time for you and for others to adjust to your new look.

You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will come back. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone who has been through cancer, like a Survivors Supporting Survivors volunteer. See page 58 for more information on Survivors Supporting Survivors.

Loss of control

'I can't cope with this.'
'I'll never get through it.'

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

>>> Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

'I used to be so healthy.'
'I had so many plans.'
'I've let my family down.'

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body that arise from treatment. Your fertility or body image may be affected by treatment. In this case the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but they will gradually fade.

Denial

'I'm fine, really.'
'I don't have cancer.'

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, people may not wish to mention or discuss their illness. Or else they may talk as if their illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

*'Why me?
I always took care of my
health.'*

'Why did this happen now?'

It is normal to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry

towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you.

Your family and friends may not always be aware that your anger is really about your illness and not towards them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. If it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

Resentment

*'How can you talk –
you don't have to
deal with cancer.'*

*'How come I'm not
getting better?'*

It is natural that you might be resentful and unhappy because you have cancer, while other people are well. During the course of your illness feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have.

You may resent having to change your lifestyle in some way. Sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

>>> Don't bottle up your feelings – express them.

Blame and guilt

*'I should have watched
my diet.' 'If only I had a
more positive attitude, I
wouldn't have got sick.'*

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time. Don't feel guilty if you can't keep a positive attitude either, especially when you feel unwell. Low periods are to be expected. There is no evidence that your attitude will affect your health or cancer. Regret and guilt serves no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

Withdrawal and isolation

*'I just need to be on
my own.'*

It is true that a cancer diagnosis can be stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700. You can also talk to one of our specialist nurses or visit a Daffodil Centre.

>>> Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness with those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



Learning to cope

After any treatment for cancer it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer. While it is true that some treatments can have some unpleasant side-effects, many people are able to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give you more support.

Survivors Supporting Survivors

Survivors Supporting Survivors is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a Survivors Supporting Survivors volunteer who has dealt with a breast cancer diagnosis. Volunteers are carefully selected and trained to give support, practical information and reassurance. Some women may also find it helpful to talk to a counsellor. Call 1800 200 700 for more information or visit a Daffodil Centre.

National Cancer Helpline Freefone 1800 200 700

Counselling

Sometimes it is difficult for people who are undergoing a stressful and emotional time to talk to the people closest to them, who may also be very upset. They may find it easier to talk to someone who is outside their immediate circle. It may be easier to untangle some of their deepest feelings and fears with someone who has been trained specifically in counselling skills. Your breast care nurse is an important source of support and can direct you to either the oncology counsellor if available or perhaps recommend a trained counsellor. A trained counsellor can provide emotional support by allowing you to express your feelings and fears, helping to make decisions and offering insight. To find out more about counselling services provided by the Irish Cancer Society and other services available in your area, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

How can my family and friends help?

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

>>> How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or



what might happen in the future. Although some people do die from cancer, many do not. Be honest with own your feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may not think you are doing much by just listening. In fact, it is one of the best ways to help.

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a copy or visit www.cancer.ie.

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while, but families can learn to adjust to changes in their lives.

Every family deals with cancer in a different way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing

for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension. If you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more. Talk to children in language they will understand and without going into the details of your illness.

It is best to prepare children for what to expect from the side-effects of treatments and to answer their questions simply and honestly. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience a range of emotions, from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring a sense of relief. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



How can I help myself?

Many people feel helpless when they are first told they have cancer. But there are things you can do at this time to feel more in control and better able to cope.

- Always ask for information that is personal to you from your own doctors.
- Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Write down the questions and answers if you want.
- Order a free *Journey Journal* from the National Cancer Helpline on 1800 200 700. It can be very useful for keeping a record of all your appointments, your telephone numbers and how you are feeling during treatment.
- Let your doctor know if you have any problems or worrying side-effects. He or she can decide what to do to help you.
- As you begin to feel better, you can set yourself some simple goals and slowly build your confidence again. Take one step at a time.
- Try to eat as well as you can. Eat little and often. Eat lots of different types of foods and plenty of fresh fruit and vegetables.
- Get some support. Join a group or call the National Cancer Helpline on 1800 200 700 and ask to be put in contact with a Survivors Supporting Survivors volunteer.
- Join a relaxation class.
- Get some regular exercise. Take it easy at first, building up the amount you do as you feel stronger.
- Some people find it helpful to talk to a counsellor.
- If the idea of changing your diet or taking exercise does not appeal to you, don't do it. Just do whatever suits you. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby.
- Research has shown that regular exercise and maintaining a healthy weight can help reduce the risk of your cancer coming back.

Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards:

- Breast care nurses
- Cancer nurse specialists
- Medical social worker
- Family doctor (GP)
- Psycho-oncology services
- Community health services
- Cancer support groups and centres
- Irish Cancer Society



Breast care nurses: These nurses are available in every specialist breast unit. They are a central point of contact during your diagnostic tests and treatment. They can give you information on all aspects of breast cancer and your treatment options. They also provide ongoing emotional support and advice.

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and cancer nurse coordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. They work together with other members of your medical team to meet your needs.

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

Family doctor (GP): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Psycho-oncology services: In some larger hospitals, there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis,

treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

Community health services: When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. All these people in community health services can provide advice and support. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Cancer support groups and centres: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. You can download the Irish Cancer Society's *Directory of Cancer Support Services* from www.cancer.ie

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

>>> Survivors Supporting Survivors can put you in touch with a volunteer who has dealt with a breast cancer diagnosis and who can support and reassure you.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drugs Payment Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or emergency department of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the emergency department first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office.

If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or local pharmacy.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some tests in advance, e.g. MRI and PET scans. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example: Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave. More information on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

Application forms for the benefits are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Appliances

If you have a medical card most appliances are free of charge. If you have had breast surgery, resulting in either partial or total breast loss, you are entitled to two free bras every year and one breast prosthesis every 2 years. If you have chemotherapy and experience hair loss, you are entitled to funding towards a hairpiece or wig during treatment. For further information, contact your local HSE office.

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See pages 72-73 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending

For a free copy of *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

For social welfare queries, contact:

Dept of Social Protection –	Tel: 1890 662 244
Information Service	Leaflet line: 1890 202 325
Oisín House	Email: info@welfare.ie
212–213 Pearse Street	Website: www.welfare.ie
Dublin 2	

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 24 1850; **Email:** info@hse.ie; **Website:** www.hse.ie

National Cancer Helpline Freefone 1800 200 700



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses as well as your normal outgoings, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to cope with your cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 72 for more details. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. See page 74 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 80 for more information.

Irish Cancer Society services

The Irish Cancer Society funds a range of services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website (**www.irishcancer.ie**) to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 77 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, please call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline 1800 200 700 or visit a Daffodil Centre to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. The booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care: Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling over 30 km to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email: travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital.

You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

See our website for more information: www.cancer.ie

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline: 1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Survivors Supporting Survivors

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone: 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Cancer Research Ireland

Website: www.cancer.ie/research

The Carers Association

Market Square
Tullamore
Co Offaly
Freefone: 1800 240 724
Email: info@carersireland.com
Website: www.carersireland.com

Citizens Information

Tel: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Dept of Social Protection – Information Service

Tel: 1890 662 244
Email: info@welfare.ie
Website: www.welfare.ie

Europa Donna Ireland

PO Box 6602
Dublin 8
Tel: 01 496 0198
Email: info@europadonnaireland.ie
Website: www.europadonnaireland.ie

Get Ireland Active: Promoting Physical Activity in Ireland

Website: www.getirelandactive.ie

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Lymphoedema Ireland

Mobile 087 693 4964
Freefone helpline: 1800 200 700
Email: info@lymphireland.com
Website: www.lymphireland.com

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health (formerly VIVAS Health)

PO Box 764
Togher
Cork
Tel: 1890 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres Dublin

[See page 76]

LARCC Cancer Support Centre

[See page 77]

For more details, call the National Cancer Helpline on 1800 200 700, email: support@irishcancer.ie or visit www.cancer.ie

Connaught support services

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 5574
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590 / 087 391 8573
Email: caraiorrais@gmail.com

East Galway Cancer Support Centre

Cluain Mhuire
Brackernagh
Ballinasloe
Co Galway
Tel: 090 964 2088 / 087 984 0304
Email: info@eastgalwaycancersupport.com
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group

Garrabeg
Gort
Co Galway
Tel: 091 648 606 / 086 172 4500
Email: info@gortcancersupport.ie
Website: www.gortcancersupport.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group
Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: info@vitahouse.org

Sligo Cancer Support Centre
44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website:
www.sligocancersupportcentre.ie

Tuam Cancer Care Centre
Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support services

ARC Cancer Support Centre
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre
ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group
25 Kings Hill
Arklow
Co Wicklow
Tel: 0402 23590 / 085 110 0066
Email:
info@arklowcancersupport.com
Website:
www.arklowcancersupport.com

Balbriggan Cancer Support Group
Unit 23, Balbriggan Business Park
Harry Reynolds Road
Balbriggan
Co Dublin
Tel: 087 353 2872 / 086 164 2234

The Bella Rose Foundation
Merry Maid House
West Park Campus
Garter's Lane
Citywest
Dublin 24
Tel: 087 320 3201
Email: thebellarosefoundation@gmail.com
Website: www.bellarose.ie

Bray Cancer Support & Information Centre
Aubrey Court
Parnell Road
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cara Cancer Support Centre
7 Williamson's Place
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: ccscdundalk.ie

Cois Nore: Cancer Support Centre Kilkenny
8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Éist Carlow Cancer Support Centre
The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre
George's Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: info@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

HOPE Cancer Support Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

LARCC Cancer Support Centre
Coole Road
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Newbridge Cancer Support Group
Tel: 083 360 9898
Email:
newbridgecancerhealinghelp@gmail.com

Rathdrum Cancer Support Centre
St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 0404 43803
Email: rathcan@gmail.com

Tallaght Cancer Support Group
Trustus House
1-2 Main Street
Tallaght
Dublin 24
Tel: 086 400 2736
Email: ctallaght@yahoo.ie
Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre
1 Morton's Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support services

Cancer Information & Support Centre
Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre
14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House
Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group
124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email:
kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven
5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.com

Sláinte an Chláir: Clare Cancer Support
Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation
Solas Centre
Williamstown
Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Suaimhneas Cancer Support Centre
2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email:
suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre
Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group
161 North Main Street
Youghal
Co Cork
Tel: 024 92353
Email:
youghalcancersupportgroup@hotmail.com

Ulster support services

Cancer Support and Social Club
Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Coiste Scaoil Saor ó Ailse
c/o Freddie O'Donnell
Knockastoller
Bunbeg PO
Letterkenny
Co Donegal
Tel: 083 121 7857
Email: saoroailse1@aol.com
Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre
The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965 / 047 62565
Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group
2nd Floor, Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Service
The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924
Email: theforgefrc@eircom.net

Useful contacts outside Republic of Ireland

Action Cancer
Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society
Website: www.cancer.org

Breast Cancer Care UK
Website: www.breastcancercare.org.uk

Cancer Focus Northern Ireland
40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Website: www.cancerfocusni.org

Cancer Buddies Network
Website: www.cancerbuddiesnetwork.org

Cancer Research UK
Tel: 0044 20 7242 0200
Website: www.cancerresearchuk.org
Website: www.cancerhelp.org.uk

Healthtalkonline
www.healthtalkonline.org

Macmillan Cancer Support (UK)
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre
Belfast City Hospital Trust
79-83 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.cancerni.net

Mayo Clinic (US)
Website: www.mayoclinic.com

Memorial Sloan-Kettering Cancer Center (US)
Website: www.mskcc.org

National Cancer Institute (US)
Website: www.nci.nih.gov

Living Beyond Cancer
Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477
Email: noreen.rodgers@hse.ie

Other support groups and centres

Cancer Care West
72 Seamus Quirke Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group
Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group
Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Killybegs Cancer Support Group
Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Solace: Donegal Cancer Support Centre
St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

Helpful books

Free booklets from the Irish Cancer Society:

- *Younger Women and Breast Cancer*
- *Understanding Breast Reconstruction*
- *Understanding Secondary Breast Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer: A Guide for Patients with Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Journey Journal: Keeping Track of Your Cancer Treatment*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*



The Breast Cancer Book: A Personal Guide to Help You Through it and Beyond

Val Sampson & Debbie Fenlon
Vermilion, 2002
ISBN 9780091884536

The Cancer Survivor's Companion: Practical Ways to Cope with Your Feelings after Cancer

F Goodhart & L Atkins
Piatkus, 2011
ISBN 9780749954857

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Mindfulness: A Practical Guide to Finding Peace in a Frantic World

Mark Williams & Danny Penman
Piatkus, 2011
ISBN 9780749953089

Not the Year You Had Planned

Cathy McCarthy
Ashfield Press, 2011
ISBN 9781901658804

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul Partnership/Limerick
VEC/Safefood, 1998
ISBN 187407514X
[For more details, see www.mabs.ie]

Helpful DVDs

Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.
Website: www.cancer.ie

A Guide to Chemotherapy

HSE/Mid-Western Cancer Centre/ICS, 2008
Call 1800 200 700 for a copy.

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.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
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.
Bone scan	A test to see images of your bones on a computer screen or on film. It can be used to find cancer in the bone.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using anti-cancer drugs.
Ducts	Tubes through which fluid passes.
Fatigue	Ongoing tiredness, often not relieved by rest.
Herceptin®	A drug used to treat breast cancer that is HER2 positive. It is a type of monoclonal antibody (a biological therapy). It binds to the HER2 protein on the surface of HER2-positive cancer cells and may kill them.
Hereditary breast cancer	A rare breast cancer that runs in families when a faulty gene is passed on by either parent. The two most common faulty genes are called BRCA1 and BRCA2.

HER2/neu	A protein involved in normal cell growth, which can also be found on some types of breast cancer cells. Cancer cells removed from your body can be tested for the presence of HER2/neu to help decide the best type of treatment for you.
Hormone therapy	The use of drugs to block the effects of the hormone oestrogen on cancer cells and stop them growing.
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.
Lymphoedema	A swelling of your arm after surgery or radiotherapy for breast cancer. It can occur if the lymph is not draining properly from your arm, because the underarm lymph nodes have been removed.
Mammogram	A special X-ray used to find a tumour in your breast.
Mastectomy	Removal of your breast by surgery.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.
Oncology	The study of cancer.
Oncotype DX®	A test that looks at the activity of 21 genes in your breast cancer cells after they have been removed. The genes are measured and a figure is calculated, which is called your individualised recurrence score. This can show your risk of the cancer returning and so help your doctor plan your treatment.

Pathologist	A doctor who specialises in examining cells which have been removed from your body.
Radiologist	A doctor who specialises in reading X-ray pictures.
Radiotherapy	The treatment of cancer using high-energy rays.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
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, when the drains have been removed.
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	Breast cancer cells that are examined in the laboratory and which do not have oestrogen receptors, progesterone receptors, or large numbers of HER2/neu protein.
Tumour	An abnormal mass of tissue caused by an overgrowth of cells. It may be benign (not cancerous) or malignant (cancerous).
Wide local excision	Surgery for breast cancer that removes the cancer along with an area of nearby tissue instead of removing the entire breast.

Questions to ask your doctor

Here is a list of questions people often want to ask. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than 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?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

>>> **Notes**

>>> **Notes**

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Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at reviewers@irishcancer.ie. If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes patient education booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email: fundraising@irishcancer.ie

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

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