

Younger Women and Breast Cancer

Caring for people with cancer





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Younger women and breast cancer

This booklet has been written to help you understand more about breast cancer in younger women. It has been prepared and checked by cancer specialists, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and 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.

| | | |
|-----|-----------------------|--------------|
| >>> | Breast care nurse | Tel: |
| | Family doctor (GP) | Tel: |
| | Surgeon | Tel: |
| | Medical oncologist | Tel: |
| | Radiation oncologist | Tel: |
| | Radiation therapist | Tel: |
| | Medical social worker | Tel: |
| | Emergency number | Tel: |
| | Treatments | Review dates |
| | | |
| | | |
| | | |

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

Breast cancer in younger women (premenopausal) is not common. In fact, most cases occur in women over the age of 50. Many younger women think that breast cancer is a disease of older women and not something they have to worry about until later in life. As a result, you may feel shocked and isolated when faced with a breast cancer diagnosis. But remember you are not alone.

Do remember that the number of women surviving breast cancer is increasing all the time. This is most likely due to the development of specialist breast units nationwide and improvements in treatments.

This booklet looks at issues you may have as a younger woman diagnosed with breast cancer. However, we do advise you to read our booklet *Understanding Cancer of the Breast*, which can help you learn more about the treatment of breast cancer. It also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. The *Journey Journal* is a useful diary to keep a record of all your test results, side-effects, and so on. These booklets are available free of charge from the Irish Cancer Society.

At the back of this booklet, you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



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 relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call 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 visit a Daffodil Centre if one is located in your hospital. See page 44 for more about Daffodil Centres.



About breast cancer

Your diagnosis

Your feelings

Being told that you have breast cancer can come as a big shock. You may have little or no knowledge of the disease but suddenly you are asked to make decisions about your treatment. Having breast cancer at a younger age may also mean that you have to make certain choices about your future sooner than you would normally.

« *Life flashed before my eyes ... kids, communions, weddings ... I cried a lot.* » MAGS

Feelings of isolation, anger and fear of dying are all common emotions to have. Asking yourself questions like ‘could I have done anything sooner?’ or perhaps ‘did I ignore the symptoms?’ are all part of the process of acceptance. Remember everyone reacts in their own way. There is no right or wrong way, just your way. Even so, always look for help and support from family, friends and health professionals.

« *It was a total shock, I didn't even have a lump, just some pain, and I was sent for a mammogram. I never expected anything to show up on it.* » DEBBI

Telling others

You may not have dealt with a serious illness before and may not know what to say to other people. It is a good idea to be as open as possible. This will help those around you to understand how you feel and be a greater support to you when you need it. Many people have cancer stories but they are not always helpful to hear. Try to remember that every situation is different.

There will be times when you will need the support of family and friends. This includes both practical and emotional support. If you have children, how much you tell them will depend on their age. Generally, it is better to be open with them about what is happening to you.

You may find some of our booklets useful to read, such as *Talking to Children about Cancer* and *Who Can Ever Understand? Talking about Your Cancer*. You can call the National Cancer Helpline on 1800 200 700 for copies or to speak with one of our specialist nurses. It can help to talk to a Reach to Recovery volunteer too.

Reach to Recovery is a group of specially selected and trained women who have been through their own breast cancer journey. They now offer emotional and practical support to those at the start of their journey.

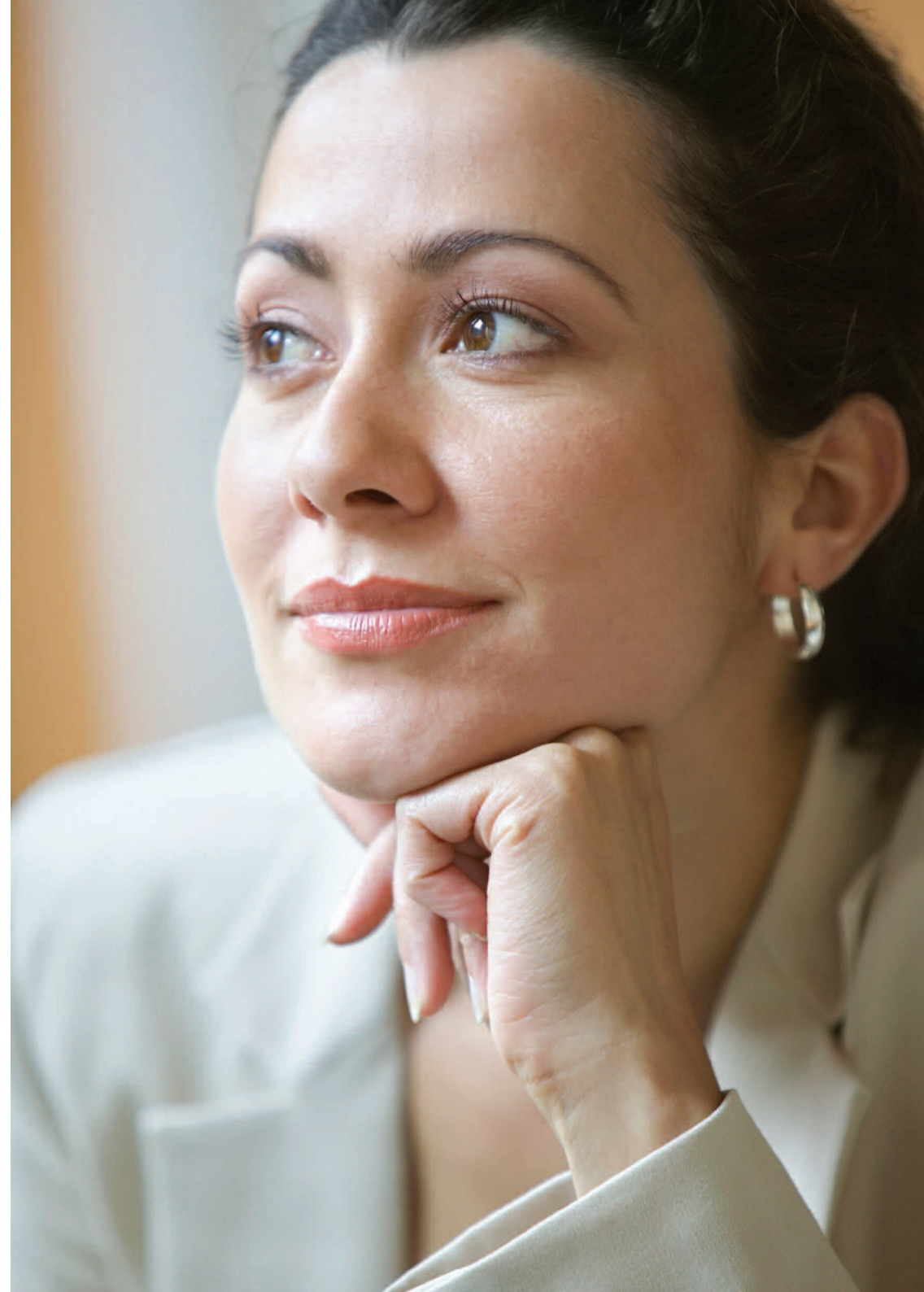
Hereditary breast cancer

Hereditary breast cancer is when you inherit a faulty breast cancer gene from either of your parents. It is also called familial breast cancer. Women who are diagnosed with breast cancer at a younger age are more likely to have a faulty BRCA1 or BRCA2 gene.

Having the breast cancer gene means that you have a higher risk of developing breast cancer. Hereditary breast cancer is not common. Only about 1 in 10 breast cancers have a genetic link. Certain factors may point to a family genetic link. These include:

- If more than two members on the same side of your family is under 50 when diagnosed with breast cancer.
- If one close relative (mother or sister) has breast cancer in both breasts.
- If there is a family history of cancer of the ovary as well as breast cancer and/or male breast cancer.
- If you have Ashkenazi Jewish heritage.

Some younger women diagnosed with breast cancer may have a family experience of breast cancer, have been to a family history clinic, or had genetic testing. If this is your case, your diagnosis may have brought up other issues.



For example, your treatment may remind you of the experiences of relatives. This can be even more difficult if a family member has died from the disease. You may also worry about it occurring in other family members, or be concerned if you have or want to have children.

If you are concerned about a family link with breast cancer, and have not been referred to a family risk clinic, talk to your breast care nurse or specialist. They will be able to advise you. If you are already attending a family risk clinic, you may want to contact them about your concerns. More information is available from the National Cancer Helpline on 1800 200 700. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.



To sum up

- Being diagnosed with breast cancer can come as a big shock. Feelings of isolation, anger and fear of dying are all common emotions to have at this time.
- There will be times when you will need the support of family and friends, both practical and emotional support.
- It can help to talk to your breast care nurse or specialist, or a volunteer from Reach to Recovery.
- Hereditary breast cancer is when you inherit a faulty breast cancer gene from either of your parents.
- Hereditary breast cancer is not common. You have a higher risk if you have a family experience of it or of ovarian or male breast cancer.

National Cancer Helpline 1800 200 700

Treatment and side-effects

Treatment issues

There are many different treatment options available to younger women. These include:

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

These treatments may be used alone or in combination. Surgery and radiotherapy are referred to as local treatments because they treat only the area where the cancer has occurred. Chemotherapy, hormone therapy and targeted therapies are called systemic treatments because they treat your whole body. Your doctor will plan your treatment by considering 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 treatment to you. This will often be because their illness takes a different form and so they have different needs.

Call the National Cancer Helpline on 1800 200 700 for more information, especially for copies of the booklets, *Understanding Chemotherapy* or *Understanding Radiotherapy*.

Fertility

Some treatments can affect your fertility. This may last for a short time or be permanent. Fertility is something you may have taken for granted and now you are faced with decisions that may affect it long term. This can be difficult, especially if you have not yet started or completed your family.

Do discuss this with your doctor before starting your treatment. It is important that you know about the side-effects of treatments and any ways of protecting your fertility. The treatments that can affect your fertility are chemotherapy, hormone therapy and ovarian ablation.



« *I'm the only woman I know who was single and had no children at the time of treatment. I felt like my life was over, and had a lot of mourning for my loss of fertility.* » EVA

In some cases, it may be possible to conceive a child in the future. Ask your doctor if you have the option of freezing your eggs before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital, Dublin provides a service where eggs and semen can be frozen and used at a later date. For example, when you have recovered from treatment. Talk to your doctor about this service or call the National Cancer Helpline on 1800 200 700 for more advice or visit the website www.hari.ie.

See page 30 for more about fertility.

Chemotherapy

Cancer cells grow in an uncontrolled way and chemotherapy works by destroying cells that grow and divide quickly. It also destroys some normal, healthy cells, which is what causes side-effects.

Chemotherapy can cause changes in your ovaries that stop eggs from being released. As a result, you might not be able to have a child in the future (infertility). Many women stop having periods while on chemotherapy. Whether your periods return or not will depend on your type of chemotherapy, the dose, and your age. The nearer you are to the menopause, the higher the risk of your periods not returning.

It can take up to a year for your periods to return after chemotherapy. It is best to talk to your doctor about the possible effects chemotherapy may have on your fertility.

« *Treatment was much easier to get through than I had anticipated. Chemo just made me very tired* » KATHY

Oncotype DX® test

The Oncotype DX® test looks at your breast cancer tissue under the microscope at a molecular level. It can then help predict how your cancer will respond to treatment. This information can help your cancer specialist plan your treatment individually. For example, if you need chemotherapy or not. The Oncotype DX® test can be used if your breast cancer is early stage, node negative, oestrogen-receptor-positive (ER+) and HER2 negative. 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.

Hormone therapy

Some women have breast cancers that are sensitive to oestrogen. This means oestrogen helps the cancer cells to grow faster. There are drugs that you can take if your breast cancer is sensitive to oestrogen. Hormone therapy works by blocking the effects of oestrogen on breast cancer cells so they cannot grow.

You may have to take these drugs for up to 5 years. Even though they do not directly affect your fertility, your doctor will advise you not to get pregnant during this time. The drugs may also hide the start of natural menopause. As a result, when you are finished the drugs, you may find that you have started the menopause. If you wish to have children and you are in your late 30s or early 40s, then taking hormone treatments for up to 5 years may be an issue you want to discuss with your specialist.

Ovarian ablation or suppression

Ovarian ablation and ovarian suppression are medical terms used to describe removing your ovaries or stopping them from working.

This may be suitable for you if your breast cancer is sensitive to oestrogen. Ovarian ablation or suppression can be achieved in three ways:

- Radiotherapy to your ovaries
- Surgical removal of your ovaries
- Hormone therapy

The effect of radiotherapy and surgery on the ovaries is permanent. This means you cannot get pregnant afterwards. Hormone therapy can also be used but the effect is usually not permanent. Once the drug is stopped, your periods should return about 6 months later. The drug commonly used is goserelin (brand name Zoladex®). It is given as a monthly injection for as long as needed up to 5 years.

Research is at present trying to find out if giving hormone therapy (usually Zoladex®) to stop your ovaries working during chemotherapy can help to protect them.

The type of ovarian ablation or suppression given will depend on your personal circumstances and your medical history. Do talk to your doctor about the options available to you.

Diagnosis during pregnancy

Being diagnosed with breast cancer during pregnancy is not common. But finding out you have breast cancer during your pregnancy or after the birth of your child may give rise to many different emotions. It may be a particularly difficult time for you and your family. Naturally, you will have many extra fears and concerns. Some women worry that their pregnancy triggered the breast cancer, but there is no evidence to prove this happens.

You will be watched closely by your oncologist (cancer doctor) and your obstetrician (pregnancy doctor). Talk to your surgeon and oncologist about the options available to you. The type of treatment offered to you will depend on the type and extent of your breast cancer. Surgery, chemotherapy and other treatments are possible during pregnancy, depending on the stage of your pregnancy.

For more about pregnancy and breast cancer, see page 30.

What are the physical side-effects of treatment?

The treatments for breast cancer can change how you feel physically and how you look. Some changes you experience may have an impact on different areas of your life. Remember that many of these changes will be temporary and there are different ways to help you at this time.

Symptoms of the menopause

Treatments like chemotherapy, hormone therapy and ovarian ablation can cause side-effects that most women would associate with the menopause. These include hot flushes, night sweats, vaginal dryness, lower sex drive, fatigue, mood changes and poor concentration. Some of these are temporary but others might not go away.

Because you are young, these side-effects can be more severe than a natural menopause. Talk to your doctor and breast care nurse about possible ways to help relieve your symptoms. They can also help you to deal with any ongoing problems.

Some women find complementary therapies helpful. Remember to check with your doctor or nurse before taking any products. Some products may not be suitable if your breast cancer is sensitive to oestrogen. For example, milk thistle, soy, black cohosh, red clover, alfalfa as well as lavender and tea tree oils used in aromatherapy.

Going through the menopause at an early age can be isolating. You may feel that you cannot share your experiences with many of your friends, or they will have little understanding of what you are going through. Don't be afraid to talk to your doctor or nurse about your feelings. They will help you find ways to cope.

For more information, contact the National Cancer Helpline on 1800 200 700. Ask for our factsheet called *Understanding and Managing Menopausal Symptoms*. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

Body image

Your treatment may change your physical appearance permanently or temporarily. Surgery might leave you with no breast and/or scarring. Some chemotherapy drugs can cause the loss of all your body hair for a short time, which can also be very distressing.

These changes in your body image may be difficult to deal with at first. They may make you self-conscious about everyday things you took for granted. For example, using a changing room in a shop. Also, some medication may cause you to put on weight. All these changes can make people around you react differently towards you. Naturally, this may be upsetting for you. But there are certain things you can do to help you feel more yourself.



Hints & Tips – ways to help you feel more yourself

- Spend time looking for a hairpiece that suits you before you start treatment.
- Look for scarves and hats that you like.
- Get used to 'pencilling in' your eyebrows.
- Ask if the Look Good...Feel Better® programme is available in your hospital. It will give you beauty tips and skincare advice.
- Ask your breast care nurse for advice.
- Be fitted professionally for your prosthesis and bra.



« I did not trust my body. It had let me down badly. »

MARY

« My lumpectomy was really successful. I feel ready to show cleavage now! I'm proud of my boobs! »

KATHY

Reconstructive surgery

Reconstructive surgery can restore the appearance of your breast. It is an option that helps a lot of women cope with losing one or both of their breasts. Reconstruction is now available in the specialist breast units around the country. Sometimes reconstruction can be done at the same time as the mastectomy, but often it is done some months

or even years after the original operation. Do discuss the options and type of reconstructive surgery available to you with your surgeon. For further information or to speak with a Reach to Recovery volunteer who has had reconstructive surgery, call the National Cancer Helpline on 1800 200 700. You can also order a copy of our booklet *Understanding Breast Reconstruction*.

« *I nearly felt more feminine than before, I was so aware of myself. I probably wore tighter clothes than before. I had an adhesive prosthesis and loved it. Then I had a reconstruction, and LOVE it. I feel pretty and womanly.* » MAGS

Discuss with others your concerns about your body image. You can also talk to a counsellor, if you think that would be helpful. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services in your area.

Sexuality

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.

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.

« *My libido was up and down. I couldn't make love without my wig on, so wearing it to bed brought a smile to my husband's face!* » AMANDA



Adjusting to changes in your life

Having to cope with both the emotional and physical effects of a breast cancer diagnosis can be very difficult. You and your partner will naturally need time to accept any changes resulting from a 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.

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 the time will feel right.

After treatment, you may find your sex drive returns, or in some cases increases due to a renewed feeling of life. But if you continue to have difficulties, discuss these with your breast care nurse. You can also talk in confidence to our specialist nurses on the National Cancer Helpline 1800 200 700.

« *My libido plummeted. Due to the side-effects of tamoxifen, physical changes normally associated with women in their 50s occurred. I was only 39. However, with patience, time and education, we have a healthy sex life again.* » AMANDA

Contraception

Even if a side-effect of your treatment is infertility and your periods may have stopped, you may still be fertile. It is important that you use a barrier method of contraception throughout your treatment. For example, a condom, diaphragm or a female condom. It is best not to use a hormone type of contraceptive, such as the contraceptive pill. Discuss this further with your cancer specialist.

National Cancer Helpline 1800 200 700

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 will 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 will continue for at least 5 years. After that, if you have had no recurrence, your care will be managed by your GP. You will still need a check-up and a routine mammogram every year.

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. You can speak to a specialist nurse, who can advise you about counselling in your area. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

Exercise after a cancer diagnosis

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 any activity that increases your breathing and heart rate and makes you become warm or sweat slightly. The pace is comfortable and you 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.



To sum up

- There are many different treatment options for younger women. These include surgery, chemotherapy, targeted therapies, radiotherapy, hormone therapy and ovarian ablation.
- Some treatments can affect your fertility. Talk to your doctor about this issue before treatment. Ask if you have the option of egg freezing at the HARI Unit.
- Chemotherapy works by destroying both cancer cells and healthy cells. This is what causes side-effects.
- Hormone therapy works by blocking the effects of oestrogen on breast cancer cells so they cannot grow.
- Ovarian ablation is a treatment for breast cancers that are sensitive to oestrogen.
- Being diagnosed with breast cancer during pregnancy is not common.
- Some physical effects of treatment include having symptoms of the menopause and changes to your body image.
- Reconstructive surgery can restore the appearance of your breast.
- Your sex life might change during and after your treatment.
- Continue to use a barrier method of contraception throughout your treatment.
- After treatment you will have regular check-up visits with your specialist.
- It may take at least a year for you to get over the effects of treatment.
- Exercising after a breast cancer diagnosis can help reduce the risk of your cancer coming back.

Coping and emotions

What are the emotional effects of breast cancer?

There is no right or wrong way to react to a breast cancer diagnosis, just your way. But there are some common experiences. Many people compare this to the stages of grieving. Knowing what these stages are can help you adjust and cope better with what is happening to you.

« *My first comment to my doctor was 'Oh God, I thought I was going to live 'til I was 100.'* » KATHY

Shock and denial

*'I can't believe it.'
'It feels unreal.'*

Shock and denial are probably the most common first reactions to a cancer diagnosis. It is natural to find yourself in a state of shock and disbelief. It is also the time when you will be receiving the most information about your disease and treatment. It can be hard to take all of it in and remember it later. Do bring someone with you at appointments to write down questions you might want answered.

Loss and anger

'Why me of all people?' 'And why right now?'

Loss can be felt in different ways. For example, the loss of how the future should have been or the loss of control of your life. The treatment you receive may prevent you from doing the things you used to in your social, work or personal life. Many women have these feelings, but you will find ways to cope and adjust to your new situation.



Fear of death

'Am I going to die?'
'Will I be in pain?'

The thought of death was probably not something you had considered before. Rather it was something to think about when you were older. Being told you have breast cancer can make you think about your own death. It may even make you feel isolated from your family and friends. And if you have children, you may be fearful that you might not see them grow up. As your coping skills develop, these fears will ease. Talking to someone who has been through a breast cancer experience or getting in touch with a support group may help. Call the National Cancer Helpline on 1800 200 700 for details of the nearest support group to you, or ask to speak with a Reach to Recovery volunteer.

Anxiety and depression

'Please leave me alone.'

At some stage, you may find yourself feeling anxious or depressed. Sometimes this may be due to feeling you are losing control of your life. Having these feelings is as much a side-effect of breast cancer as any physical side-effects. If the feelings go deeper than anxiety and you think you may be depressed, then you should seek professional help. Ask your GP or breast care nurse for advice. There may be a specialist cancer counsellor available in the hospital or cancer drop-in centre. The Irish Cancer Society also has specialist cancer counsellors, so do call our freefone helpline 1800 200 700 for more information.

Acceptance

At some point you will realise that life has to go on. The ordinary day-to-day organising and living of life starts to overshadow the cancer and its treatment. The other stages may still crop up, but with time they become less intense and less frequent.

Remember to take time out for yourself once a day. This means taking time away from work, family and the general hustle and bustle of life.

Tell yourself positive things about yourself, read a book, listen to music or meditate. Do whatever you can do to recharge yourself. If you like, call the National Cancer Helpline on 1800 200 700 for a copy of the useful booklet, *Understanding the Emotional Effects of Cancer*.

How will my relationships be affected?

Cancer not only affects you, the person diagnosed with it, but also those around you. The impact can be far-reaching. How well those closest to you cope can also affect how you adjust and cope. Most people have at some stage in their lives been affected by cancer – either a family member or a friend. Every experience is different. Just like every person with cancer is different, so too is his or her experience with the disease.

Your partner

Most young couples do not think they will have to deal with a serious illness at a young age. A serious illness can change the roles each of you play within your relationship. For example, your partner may have to take a more active role in the running of the house or managing the children. Some partners may become very protective, while others take a paternal role. Some may research as much information on the disease as possible, while others withdraw.

« *My husband was so upset for both of us. We were so scared of what the future would hold. We had to deal with so many emotions together. It was so hard at first.* » OLWYN

Everyone is different in how they cope with a situation. Remember there is no right or wrong way. The most important thing is for both of you to express your concerns openly and honestly. At times your partner may feel isolated and unable to express his or her feelings and concerns. Support is available for your partner from local support groups or from the counsellors available through the National Cancer Helpline. Call 1800 200 700 for more information.

Your children

You may find that your relationship with your children changes after your diagnosis. How you discuss your breast cancer and treatment with them will depend on their age and character. Children can often sense that there is a problem. And if they are not told about it, their imagination will think the worst.

A child's view of time is very different to an adult's. If you are in hospital for a few hours or a few days, it can seem like a very long time for a young child. Do let them know about your appointments or hospital visits.

Children need to know and be reassured that you will be coming back. If they are unaware of what is going on, they may feel abandoned and frightened. Explain in words that you have used before when you or someone else were sick. Tell them that you are going to hospital to be made better.

« *My 12-year-old daughter watched me very closely. If I was down, she was down.* » AMANDA

Children react differently. Some may become 'clingy', while others distance themselves or become disruptive. Your role as a mother may change too. You may not be able to do the school run or have the energy to play or do activities with them like before. But this will return in time.

You may be surprised at just how much children pick up and remember, no matter how young. They can suddenly come up with a comment or question months or even years after your treatment. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* is available from the National Cancer Helpline on 1800 200 700. See page 54 for more details on books written for children whose parents have been diagnosed with cancer. The medical social worker at the hospital can also help you to explain cancer to your children.

Your family and friends

Your parents may find it hard to cope with the fact that their child has a serious disease. Generally, family and friends can be a good source of support, both emotionally and physically. For example, cooking meals for you, helping with housework and childcare, and listening to your worries.

Although people mean well sometimes, they can begin to define you by your cancer. As a result, the real you may feel lost. Some people may withdraw out of fear and lack of experience. Others may not understand that you feel too unwell to go out. Tell them how you feel or, if you cannot, ask another family member or friend to tell them.

You may find our booklets useful, such as *Who Can Ever Understand? Talking about Your Cancer* or *Lost for Words: How to Talk to Someone with Cancer*. Contact the National Cancer Helpline on 1800 200 700 for copies. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

« *Some people are embarrassed by cancer and think that you become a different person when you are a cancer patient.* » DEBBI

Looking to the future

After your surgery and treatment is over, families and friends may expect you to go back to 'normal'. But it does not always happen that way. You may still have some side-effects of treatment, such as fatigue and hot flushes.

Some women find that a year after treatment when the routine of hospital visits and contact with doctors and nurses is reduced, it is then that they begin to feel low. The reality of the past few months may then hit hard. But this is normal. If it happens to you, contact the National Cancer Helpline on 1800 200 700 and we can put you in touch with support services.

With time your breast cancer will become a lesser part of your life. You will start to look forward to resuming old plans that were put on hold and planning your future. Breast cancer might change your outlook on life. It may make you review your life and the important things in it. Above all, it may give you a renewed zest for life.

« *I realised that I didn't want to climb Mount Everest or go on a world cruise, but wanted to see my children and garden grow. Life's simple pleasures!* » MARY



To sum up

- There is no right or wrong way to react to a breast cancer diagnosis, just your way.
- Some reactions include shock and denial, loss and anger, fear of death, anxiety and depression, acceptance.
- Your illness might affect your relationships with your partner, children, family and friends.
- Do ask your breast care nurse or medical social worker for advice.
- Counselling can be arranged if you need it.
- Some women need more support a year after treatment, when everything has gone 'back to normal'.



Long-term issues

Financial worries

A diagnosis of cancer can sometimes bring the added burden of financial worries. This can be difficult if you cannot work, can only work part-time or are unemployed. You may find you have a lot more expenses as well as your normal outgoings. This includes medication, travel, food, heating, laundry, clothing and childcare costs.

There is help available if you find it hard to cope with all these expenses. You may be entitled to benefits and allowance. Do ask the medical social worker in your hospital, your local social welfare office or Citizens Information 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. These schemes are called Travel2Care and Financial Aid. See page 47 for more details. You can also call the National Cancer Helpline on 1800 200 700 for ways to help you manage.

If you are finding it hard to repay your mortgage or rent, talk to your bank or property owner to see if you can come to some arrangement with them. Having cancer may also affect your chance of getting a mortgage, a loan or insurance in the future. Talk to the medical social worker in the hospital or a financial adviser about any money issues you may have. A useful booklet available from the Irish Cancer Society is *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. Call 1800 200 700 for a copy or visit a Daffodil Centre if one is located in your hospital.

Getting into debt

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 48 for more contact details.

Employment

Your diagnosis and treatment may affect how you do your job. Or it may be unsuitable for you to continue. For example, if you have had lymph nodes removed from your arm, you may not be able for heavy lifting or a lot of typing. If you have had chemotherapy or radiotherapy, you may be fatigued for some months. Do talk to your employer about reducing your hours or taking leave of absence. You might also need to think about a career change.

On the other hand, if your job is suitable and you do not feel too fatigued, it might be good for you to return to work. It can help you to regain some sense of normality in your life. You will need to make a decision based on:

- Your individual treatment plan
- Advice from your breast care nurse and oncologist
- The type of work you do
- How flexible your employer is
- If you need to receive sick pay and for how long

Pregnancy after breast cancer

Getting pregnant after breast cancer treatment does not appear to increase any risk of the cancer returning. Most oncologists advise that you wait at least 2 years after the end of treatment before you try to get pregnant. If you wish to get pregnant, discuss your options with your doctors.

Fertility

The nearer you are to menopause, the less likely your fertility will return after treatment. If you had menopausal symptoms during your treatment and your periods have not returned about a year after your treatment ends, you may be infertile. Your doctor may arrange a blood test to check your hormone levels. This will show if you have gone through the menopause or not.

« *Infertility was the worse part of all. Losing my hair and feeling sick paled in comparison. I still get upset even now ... but counselling has helped.* » KATHY

Being told that the treatment for your cancer has made you infertile can be devastating. The sense of loss is very real – for the children you will never have or for the brothers or sisters your children will never have. However, 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.

Bone health and osteoporosis

The hormone oestrogen helps to keep your bones healthy and strong. Without it, bones can become weak and thin, and osteoporosis can occur. You will be more prone to fractures as a result. Some treatments for breast cancer can cause bone weakness. This is due to the early start of the menopause. Ask your doctor to check if you are at risk of osteoporosis, so you can discuss your options with him or her.



To sum up

- There is help available if you have financial worries. Talk to the medical social worker in your hospital, your local social welfare office or Citizens Information Centre.
- You might qualify for two schemes by the Irish Cancer Society: Travel2Care and Financial Aid.
- If your job is unsuitable to return to, talk to your employer about reducing your hours or taking leave of absence. You might think about a career change too.
- Getting pregnant after breast cancer treatment does not appear to increase the risk of the cancer returning.
- It is best to wait 2 years after treatment before getting pregnant.

- To find out if you can get pregnant, your doctor will arrange blood tests that check your hormone levels.
- Some treatments for breast cancer can cause bones to weaken and thin (osteoporosis). Ask your doctor to check if you are at risk of osteoporosis, so you can discuss your options with him or her.

Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards. Remember you are not on your own. Some young women find all the support they need from those around them, family and friends. Others feel quite isolated and unsupported. The support of others with breast cancer and health professionals specialising in the area of young women with breast cancer can be a great benefit too.

« Talk about it openly with one or two people if you can ... it clears your mind. Also get busy! We landscaped our garden during this time, a great distraction and pure escapism. »

MARY

You may not feel like ‘burdening’ those close to you and have a need to protect them. However, there are many people ready to help you and your family throughout treatment and afterwards. For example:

- 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 along with other members of your medical team work together 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. For example, Reach to Recovery. 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.

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 for information about any of the services outlined above or for support services in your area. Or you can visit a Daffodil Centre if one is located in your hospital.

>>> Reach to Recovery has a network of trained volunteers throughout the country who can visit you in hospital or in your home.

Online support: There are now many online chatrooms and support services available to young women dealing with their specific issues. Some are run by the women themselves, others are run by organisations. Helpful sites with open forums and chat facilities include:

- www.cancer.ie
- www.breastcancercare.org.uk
- www.breastcancer.org
- www.youngsurvival.org

See page 43 for more details about Irish Cancer Society services.

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
- Drug Payments 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 A&E unit 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 A&E unit 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 50c per item up to a limit of €10 per family.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €700 or less, 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. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

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.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €132 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. You can also register for this scheme by filling in a registration form at your 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 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, for example, MRI and PET scans. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care.

You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home.

More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Leave

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave.

You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

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 can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your 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. Sometimes the HSE may assist with transport costs if you have to travel a long distance to the hospital.

In general, if you do not have a medical card, you may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

A useful booklet available from the Irish Cancer Society is *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. Call 1800 200 700 for a copy or visit a Daffodil Centre if one is located in your hospital.



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 social welfare queries, contact:

Dept of Social Protection – Information Service
 Oisín House
 212–213 Pearse Street
 Dublin 2

Tel: 1850 662 244
 Leaflet line: 1890 202 325
 Email: info@welfare.ie
 Website: www.welfare.ie

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

HSE East Coast Area
 [Co Wicklow, South East Dublin]
 Southern Cross House
 Southern Cross Business Park
 Boghall Road
 Bray
 Co Wicklow
 Tel: 01 201 4200

HSE Northern Area
 [North Dublin]
 Swords Business Campus
 Balheary Road
 Swords
 Co Dublin
 Tel: 01 813 1800

HSE South Western Area
 [Co Kildare, West Wicklow, South Dublin]
 Oak House
 Millennium Park
 Naas
 Co Kildare
 Tel: 045 880 400

HSE Midland Area
 [Counties Laois, Offaly, Longford, Westmeath]
 Head Office
 Arden Road
 Tullamore
 Co Offaly
 Tel: 057 932 1868

HSE Mid-Western Area
 [Counties Clare, Limerick, Tipperary North]
 Head Office
 31/33 Catherine Street
 Limerick
 Tel: 061 483 286

HSE North Eastern Area
 [Counties Cavan, Monaghan, Louth and Meath]
 Head Office
 Navan Road
 Kells
 Co Meath
 Tel: 046 928 0500

HSE North Western Area
 [Counties Donegal, Sligo, Leitrim and West Cavan]
 Head Office
 Manorhamilton
 Co Leitrim
 Tel: 071 982 0400 / 1850 636 313

HSE South Eastern Area
 [Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]
 Head Office
 Lacken
 Dublin Road
 Kilkenny
 Tel: 056 778 4100

HSE Southern Area
 [Counties Cork and Kerry]
 Head Office
 Wilton Road
 Cork
 Tel: 021 454 5011

HSE Western Area
 [Counties Galway, Mayo and Roscommon]
 Head Office
 Merlin Park Regional Hospital
 Galway
 Tel: 091 751 131

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

Citizens Information

Citizen Information Service: 0761 07 4000

Email: info@ciboard.ie; Website: www.citizensinformation.ie

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
- 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** 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 freefone helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- 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, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. These 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 49 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.



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 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 a number of 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

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Society.

Financial support

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

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.

Travel2Care: 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: For this kind of help, 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 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 0566 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

Reach to Recovery

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

Europa Donna Ireland

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

Cancer Research Ireland

Website:
www.cancer.ie/research/why.php

Citizens Information

Citizen Information Service: 0761 07 4000
Email: info@ciboard.ie
Website: www.citizensinformation.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All-Ireland Cooperative Oncology Research Group

Website: www.icorg.ie

Lymphoedema Ireland

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

Irish Nutrition & Dietetic Institute

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

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 0761 07 2000
Freefone 1890 283 438
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health (formerly VIVAS Health)

PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.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 and Cork (see pages 50 and 51).

Reach to Recovery

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

I've Got What?!

[Support for young adults affected by cancer]

c/o Cross Cause Charity Shop
Blackrock
Co Louth
Tel: 086 339 5690

St Luke's Breast Cancer Support Group

Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5163

Connaught support groups & centres

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre

Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cancer Care West

Inis Aoibhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cara Iorrais Cancer Support Centre

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

East Galway Cancer Support Centre

The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website:
www.eastgalwaycancersupport.com

Gort Cancer Support Group

The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: www.gortcs.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: vitahouse@eircom.net

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 groups & centres**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 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

The Bellarose Foundation

Women with Cancer
Merry Maid House
West Park Campus
Garter Lane
Citywest
Dublin 24
Tel: 086 879 3242
Email: thebellarosefoundation@gmail.com

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.com
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support

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

Dundalk Cancer Support Group

Philipstown
Hackballs Cross
Dundalk
Co Louth
Tel: 086 107 4257

Éist: Carlow Cancer Support Group

Rathornan
Leighlinbridge
Co Carlow
Tel: 085 144 0510

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: phil@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

Haven Cancer Support and Therapy Group

Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

HOPE Cancer Support Centre

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

Kilkenny Cancer Support Services

Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Rathdrum Cancer Support Centre

34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Stillorgan Cancer Support

c/o Marsham Court
Stillorgan
Co Dublin
Tel: 01 288 5725

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: ctallaght@yahoo.ie

Wicklow Cancer Support Centre

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

Munster support groups & centres**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: cancersupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Kerry Cancer Support Group

124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@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.org

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
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas 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 / 087 273 1121

West Cork Cancer Support

Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

Ulster support groups & centres**Breast Centre Northwest**

Geraldine McGregor
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 910 4600

Cancer Support and Social Club

Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

The Forge Cancer Support Group

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

Good and New Cancer Drop In Centre

Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

Solace: Donegal Cancer Support Centre

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

Yana Cancer Support Centre

Belturbet
Co Cavan
Tel: 087 994 7360

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 Network Buddies

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

Young Survival Coalition (US)

61 Broadway, Suite 2235
New York, NY 10006
Email: info@youngsurvival.org
Website: www.youngsurvival.org

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Cancer of the Breast*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and 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, 2000
ISBN 9780091884536

Sexuality and Fertility after Cancer

Leslie R Schover
Wiley, 1997
ISBN 0471181943

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

F Goodhart & L Atkins
Piatkus, 2011
ISBN 9780749954857

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul Partnership/Limerick
VEC/Safefood, 1998
ISBN 187407512X
[For more details, see www.mabs.ie]

Not The Year You Had Planned

Cathy McCarthy

Ashfield Press, 2011
ISBN 9781901658804

Explaining cancer to children

The Secret C: Straight Talking About Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1853908916

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?

| | |
|-----------------------------|--|
| Biological therapy | A treatment that uses your body's immune system to fight cancer. It can target the cancer cells directly. Also called targeted therapies. |
| Chemotherapy | A treatment using drugs that cure or control cancer. |
| Hormone therapy | A treatment that uses hormones to cure or control cancer. |
| Medical oncologist | A doctor who specialises in treating cancer patients using chemotherapy and other drugs. |
| Oestrogen | A female hormone made by your ovaries. Some breast cancers are sensitive to oestrogen, which helps them to grow faster. |
| Oncology | The study of cancer. |
| Ovarian ablation | A treatment for oestrogen-sensitive breast cancer. Surgery, radiotherapy or hormone therapy is used to stop the ovaries from making the hormone oestrogen. |
| Postmenopausal | After the menopause. |
| Premenopausal | Before the menopause. |
| Radiation oncologist | A doctor who specialises in treating cancer patients using radiotherapy. |
| Radiotherapy | The treatment of cancer using high-energy X-rays. |
| Targeted therapies | Another name for biological therapies. |

National Cancer Helpline 1800 200 700

Questions to ask your doctor

When you visit your doctor, it can be hard to think of questions you want to ask or to remember the answers. It may help to bring someone with you to your appointments. Or ask your doctor if you can tape the conversation. These sample questions below may help. You can also use the *Journey Journal* to write down your questions and answers.

- What stage and grade is my cancer?
- What are my treatment options?
- What are my surgical options?
- Can I take time to decide my treatment options, and how long can I take?
- How long will the treatment last?
- Are there any new clinical trials I could take part in?
- Does my diagnosis affect the risk for other members of my family? What should they do?
- What support services are available during and after my treatment?
- How often should I have check-ups after I finish treatment?

Side-effects and precautions

- What are the side-effects of the treatment, including menopausal symptoms?
- How long will the side-effects last?
- Will treatment affect my fertility?
- Is there anything that can be done to protect my fertility for the future?
- Can I be referred to the HARI Unit for egg freezing?
- What contraception should I use?
- Will the treatment affect my bones in the future?

« Bring a friend with you. Take notes if you want, and don't be afraid to ask questions until you're satisfied. » EVA

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

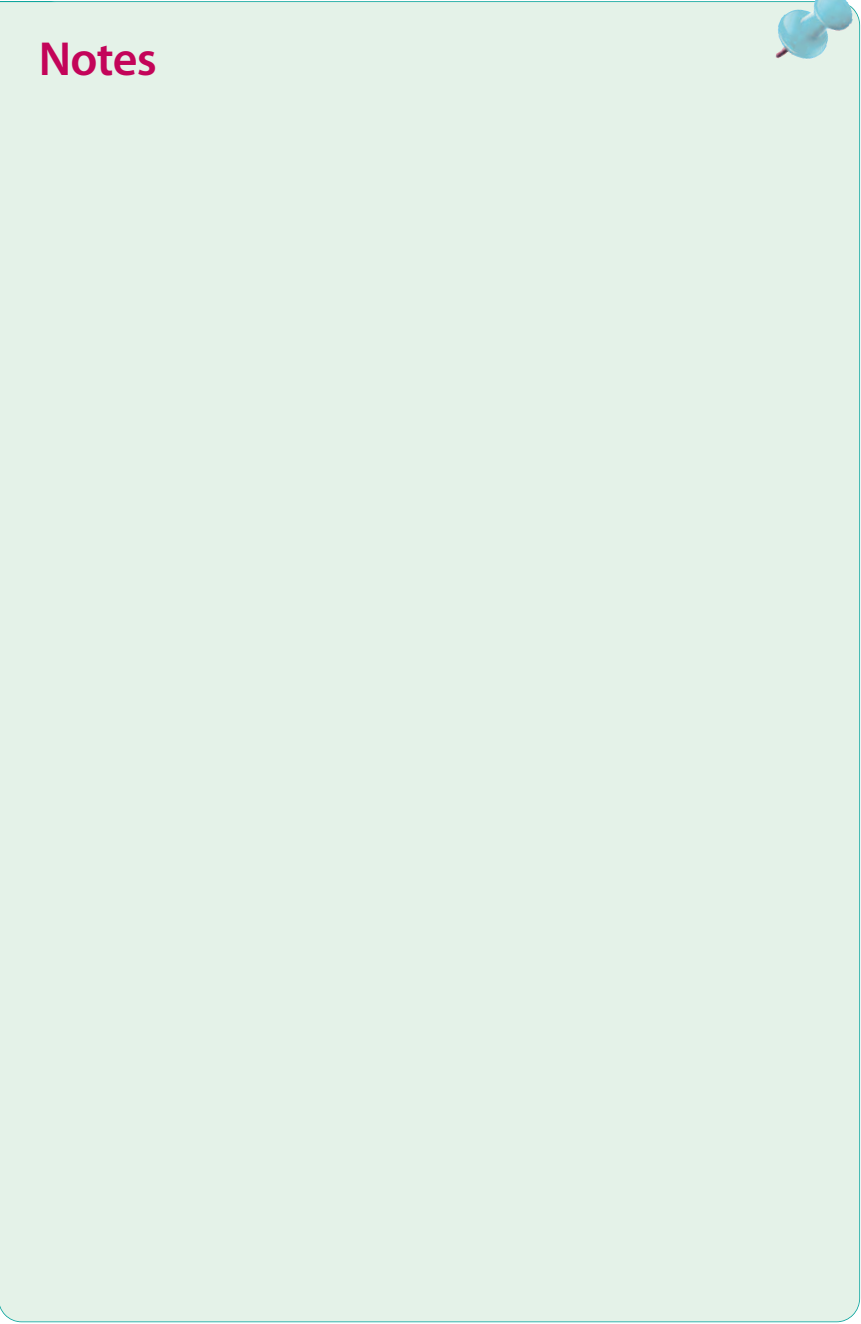
5

Answer

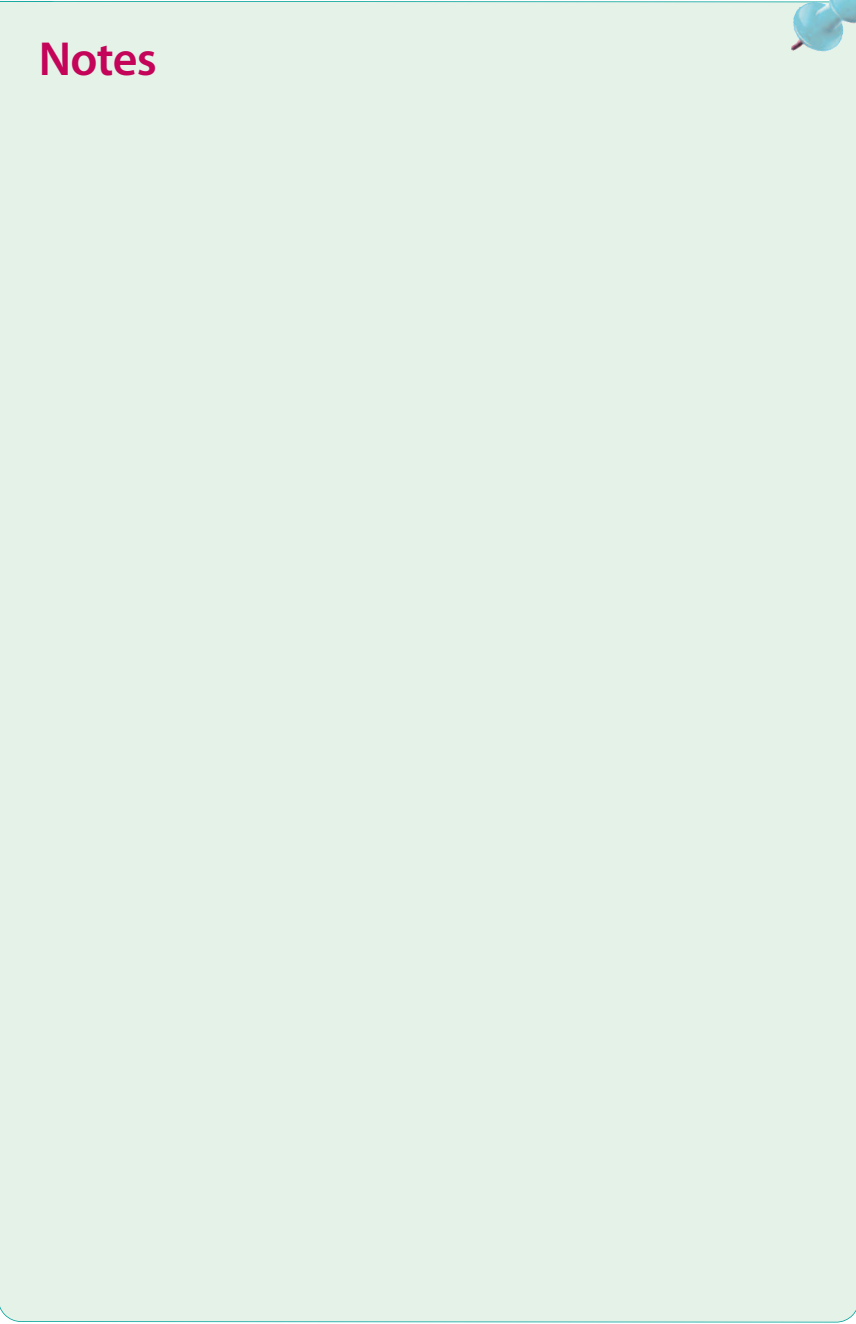
6

Answer

>>> **Notes**



>>> **Notes**



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Jennifer Nestor, Cancer Information Nurse

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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. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

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

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.

