

Coping with Advanced Breast Cancer



Marie Keating
FOUNDATION

Making cancer less frightening by enlightening

About this booklet

This booklet is about coping with advanced breast cancer symptoms, strong emotions, and other difficulties people may face when they receive a diagnosis that their breast cancer has spread.

Not everyone is ready to read about what happens when someone has a terminal illness. Some of the information here can be upsetting and difficult to cope with. If you do read on, we suggest you have someone close by to support you.

We hope that we can give you the practical information, support and comfort you may need during a very emotional and difficult time.

Contributors

With thanks to Evelyn Wakefield, Dr Miriam O'Connor, Tara Byrne, Dr Sinead Lynch, Dr Aisling O'Gorman and Vicki McCullagh

Contents

What is advanced breast cancer?.....	4
Your emotions and cancer.....	33
Evelyn Wakefield tells us about living with advanced breast cancer...40	
Diet and nutrition.....	47
Avoiding and managing lymphoedema	53
Coping with the financial implications of cancer	62
Making the most of every day	68
Coping psychologically with terminal illness.....	72
Palliative care is not just for end of life	77
Planning ahead: think ahead.....	82
Useful organisations, contacts and supports.....	90
Index	102

What is advanced breast cancer?

Advanced breast cancer is breast cancer that has spread beyond the breast to other organs in the body, most often the bones, lungs, liver or, less commonly, the brain.

There are many words used for this condition that can make it sound complicated, however, a lot of the words mean the same thing.

Advanced breast cancer is also called:

- metastatic breast cancer;
- stage 4 breast cancer; or
- secondary breast cancer.

Main types of advanced breast cancer

There are three main subtypes for advanced breast cancer.

1. The most common type is hormone driven – by oestrogen or progesterone.
2. The second commonest group is HER2.
3. The third most common is triple negative (this mean oestrogen, progesterone and HER2 are absent or negative).

Symptoms of advanced breast cancer

It might not mean that you have advanced cancer if you have these symptoms. They can be caused by other conditions:

- feeling tired;
- low energy levels;
- feeling ‘under the weather’;
- having less appetite;
- weight loss; or
- pain.

It might not mean that you have advanced cancer if you have these symptoms. They can be caused by other conditions.

The symptoms you may experience will depend on where in the body the cancer has spread to. You might not have any of the symptoms mentioned here. However, if you have symptoms that you are worried about, discuss them with your:

- GP;
- cancer specialist; or
- breast care nurse or surgeon.

Where cancer can spread

The most common places for breast cancer to spread are the:

- lymph nodes;
- bone;
- liver;
- lungs; and
- brain.

Symptoms if cancer has spread to the lymph nodes

Lymph nodes are part of a system of tubes and glands in the body that filters body fluids and fights infection.

The most common symptom if cancer has spread to the lymph nodes is that they feel hard or swollen. You might have some of the following symptoms if your cancer has spread to the lymph nodes:

- a lump or swelling under your armpit;
- swelling in your arm or hand (lymphoedema); or
- a lump or swelling in your breast bone or collar bone area.

One of the first places breast cancer can spread to is the lymph nodes under the arm on the same side as the breast cancer. This is not advanced cancer.

Symptoms if cancer has spread to the bones

You may have some of these symptoms if your cancer has spread to the bones:

- an ache or pain in the affected bone; or
- a weakened bone which is more prone to break or fracture.

Symptoms if cancer has spread to the bones

You may have some of these symptoms if your cancer has spread to the bones:

- an ache or pain in the affected bone; or
- a weakened bone which is more prone to break or fracture.

Sometimes when bones are damaged by advanced cancer, the bones release calcium into the blood. This is called hypercalcaemia and can cause various symptoms like:

- tiredness;
- feeling sick (nausea);
- constipation;
- irritability;
- thirst; or
- confusion.

Symptoms if cancer has spread to the liver

You may have some of the following symptoms if cancer has spread to your liver:

- tiredness;
- discomfort or pain on the right side of your tummy (abdomen) where the liver is;
- feeling sick (nausea);
- loss of appetite;
- a swollen abdomen; or
- yellowing of the skin or itchy skin (jaundice).

Symptoms if cancer has spread to the lungs

You may have some of these symptoms if your cancer has spread into the lungs:

- a cough that doesn't go away;
- breathlessness;
- ongoing chest infections;
- coughing up blood; or
- a build-up of fluid in the lining around the lung (a pleural effusion).

Symptoms if cancer has spread to the brain

Cancer that has spread to the brain can cause different symptoms depending on where in the brain is affected. You might have some of these symptoms:

- headaches or feeling sick;
- weakness or numbness in your limbs;
- memory problems;
- behaving in a way that is unusual for you; or
- problems with your eyesight.

What does 'secondary' mean?

When talking about a specific area of the body or 'site' where the advanced breast cancer has spread, the term 'secondary' is often used, for example 'breast cancer with a secondary in the bone'.

What does 'metastases' mean?

The word 'metastases' is sometimes also used to describe these sites, for example, 'breast cancer with bone metastases'.

The original cancer in the breast is referred to as the 'primary' cancer.

If it has spread to your bones it is still breast cancer

When breast cancer has spread to another part of the body, it is still considered and treated as breast cancer. For example, breast cancer that has spread to the bones is still breast cancer (not bone cancer).

This is because when cancer cells that begin in the breast spread to any other part of the body, they don't change and are still breast cancer cells.

This means that breast cancer that spreads to any other part of the body will respond best to drugs specifically designed to treat breast cancer.

'De novo' breast cancer

Sometimes people are found to have advanced breast cancer at the time they notice the primary in their breast. This is called 'de novo' advanced breast cancer.

Recurrent advanced breast cancer

It is more common for advanced breast cancer to develop in the months or years (sometimes more than 20 years) after a person has completed treatment for early breast cancer.

Why did I get advanced breast cancer?

It is not known why some breast cancers spread and cause secondaries and others don't. It is also not known why some spread very early, and may result in de novo advanced breast cancer, and others do not spread for many years.

Treatments for a early breast cancer look to reduce the chance that the cancer will spread to other body parts, but they don't come with a

100% guarantee. These treatments include:

- surgery;
- radiotherapy;
- chemotherapy;
- targeted therapies; and;
- hormone therapies.

There is no evidence that specific events, such as an operation, another illness or a stressful life event cause advanced breast cancer.

Why was it not found earlier?

First of all, it is important to understand that finding advanced breast cancer earlier does not change the results of treatment. Whenever advanced breast cancer is found, it can be treated, but cannot currently be cured.

The results of treatment are just as good whether it was found a few months ago or now. The only exception to this is if the cancer has reached a very advanced stage making you very unwell — treatments may not be able to be given, or may not work very well or may cause additional symptoms for you. Advanced breast cancer usually does not get to this stage without a person being aware of being unwell.

How long will I live?

When you are diagnosed with advanced breast cancer it is natural to wonder how long you have to live. This is difficult to answer because no two people and no two cancers are the same. A number of factors affect survival times for people with advanced breast cancer, including:

- the subtype of breast cancer (hormone receptor positive, HER2-positive and triple negative);
- the site of metastases;
- response to treatment;
- time since treatment for early breast cancer; and
- the presence of other health issues not related to cancer.

If you wish to talk to your specialist about the likely progress of your disease, you have a right to clear and honest answers. Having a good relationship with your treatment team, where you can communicate openly and honestly, is important as you approach these sorts of conversations. Before you ask about your prognosis, you need to think about how this information will affect you.

Keeping a diary can be helpful

Evelyn Wakefield (see Section 3: how does it affect you?) has advanced breast cancer and says it is very helpful to keep a diary where you write details of:

- any questions you may have;
- symptoms;
- medication you are taking;
- if you have any pain;
- if you are experiencing nausea;
- fatigue; and
- any other issues you are concerned about.

*Written in consultation with Oncology Consultant,
Dr Miriam O'Connor, of Waterford Regional Hospital*

How does advanced breast cancer affect you?

Oncology Consultant, Dr Miriam O'Connor, of Waterford Regional Hospital, talks to the Marie Keating Foundation

What should a woman watch out for during treatment?

If you have new, persistent or progressive worsening of a symptom, you should have it checked out. The first port of call whether it is early or advanced cancer is your GP. People with advanced cancer may have other problems as well and you don't always need hospital care to treat it. If your GP is unable deal with it then it is likely that you will be referred to the hospital. At the hospital the main people you will see will be the:

- oncology consultant;
- the oncology liaison nurse; and
- day-ward nurse or
- breast care nurse or doctor.

What questions should a woman ask

Bring a list of questions to appointments. If you don't have them written down, you may forget what you wanted to ask. If possible bring someone with you who can take note of what the doctor says. It is a stressful situation and it is difficult to remember everything.

Interview: How does advanced breast cancer affect you?

Questions for your first appointment

Here are some questions you can ask at your first appointment.

- Where is my cancer?
- Where are the secondaries?
- What type of advanced breast cancer is it?
 - hormone (oestrogen or progesterone) driven,
 - HER2 driven, or
 - triple negative?
- What kind of treatment or treatments can I have and what is my likely quality of life that I can expect on this treatment?
- Is there a clinical trial open to me? – and if so, what would that mean for me?

Questions for your second appointment

- Is the treatment working?
- I have side effects, how can I manage them?
- When will I need to come back again?

Difficult questions

Dr O'Connor says that some women want to know the success rates and timescale of treatment, and others don't. When you are first diagnosed, you may want to know how much time you are likely to survive with your advanced breast cancer. This is a question you can ask your doctor. The average woman used to live with advanced breast cancer for 2-3 years, but with progress in treatment and managing side effects from treatment, many women now live for many years.

“Prognosis is very difficult to predict with the advances in treatment. Some people live for years and manage many types of treatment during those years. Some people do not tolerate treatment. Many people struggle with the diagnosis and the idea of life- long treatment. Some people are very keen on estimates on prognosis, but can struggle to move beyond the information to focus on living every day to the full” said Dr O’Connor.

Can I get a second opinion?

“If anyone asks me about having a second opinion, I say ‘Absolutely, who do you want to go to?’” says Dr O’Connor.

“Some people advise me they are seeking a second opinion and others don’t. They might ask me who to go to and I send the necessary information. To get the most out of a second opinion, the person needs to bring as much information as possible about what has happened to them already,” says Dr O’Connor.

Future therapies

New drugs and therapies becoming available all the time. Stem cell and gene therapy are not available yet.

“New therapies tend to focus on the pathways that allow advanced breast cancer to develop. These therapies have to succeed in clinical trials to ensure they work before they are given a licence for use in advanced breast cancer,”says Dr O’Connor.

Coping with your diagnosis

Finding out that you have an advanced cancer can be a shock. It's common to feel uncertain and anxious and it's normal to be unable to think about anything else.

Lots of information and support is available to you and your family and friends. It can help to find out more about your cancer and the treatments you might have. Many people find that knowing more about their situation can make it easier to cope. Talk to your specialist to understand:

- what your diagnosis means;
- what is likely to happen;
- what treatment is available; and
- how treatment can help you.

It is also difficult to cope practically and emotionally. At first, you are likely to feel very upset frightened or confused. You may feel that things are out of your control.

It is very important to get the right information about your type of cancer and how it is best treated. People who are well informed about their illness and treatment are more able to make decisions and cope with what happens.

Coping practically with advanced breast cancer

As well as coping with the fear and anxiety that a diagnosis of advanced breast cancer brings, you may also have to work out how to manage practically. There may be money matters to sort out. You may need information about financial support like:

- benefits;
- sick pay; and
- grants.

See the later in this booklet: 'Coping with financial implications'.

Ask for help

Just try to remember that you don't have to sort everything out at once. It may take some time to deal with each issue. Do ask for help if you need it. Your doctor or specialist nurse will know who you can contact for help. They can put you in touch with people specially trained in supporting those with cancer. These people are there to help so do use them if you feel you need to.

Staff can support you

You may need access to support staff like a specialist wound-care nurse. Social workers can help you with information about your entitlement to sick pay and benefits. If you live alone, a social worker may be able to help by organising convalescence when you first come out of hospital.

Interview: How does advanced breast cancer affect you?

What to expect

Your specialist will take a number of different factors into account when deciding which treatment is best for you, including:

- which part of your body the cancer has spread to;
- the treatment you have already had;
- your general health;
- if you have had your menopause;
- if the cancer is growing slowly or more quickly; and
- if the cancer cells have receptors for particular types of drug treatment.

Advanced breast cancer may respond to several types of treatment. Doctors try to start with treatment that has as few side effects as possible. Remember that treatment can often keep advanced breast cancer under control for many months or years.

What type of treatment will I need?

When you are first diagnosed with advanced breast cancer, it can be a roller coaster. You may present with a breast lump, but you may also have bone cancer affecting your spine. You may have appointments with:

- a breast surgeon;
- oncologist;
- radiation specialist; and
- an orthopaedic surgeon.

This can all make the beginning very bewildering. However, after a couple of months things settle down and you will mostly see just the oncologist.

Managing symptoms and side effects

Managing cancer fatigue

We all feel fatigue at times – maybe when we are working too hard, worrying about something or just doing too much partying! Fatigue for people with cancer can be very different. The cancer or its treatment may make you feel very tired. It can go on for weeks, months or even years. This is called chronic fatigue – chronic means long lasting.

Radiotherapy and fatigue

Most people feel tired while they are having radiotherapy, particularly if they are having treatment over several weeks. This is because the body is repairing the damage to healthy cells. Or tiredness can be due to low levels of red blood cells (anaemia).

You may also feel weak and as though you don't have the energy to do your normal daily activities. This may last for a few weeks after the treatment ends. Rest if you need to and try to exercise a little when you can. This may help to reduce the tiredness.

Fatigue is common

Fatigue is very common in people with cancer. It can be the most troubling symptom. It affects between 7 and 9 out of every 10 people (70 to 90%) with cancer. Many people say that it is the most disruptive side effect of all. In the past, doctors and nurses haven't always appreciated the long-term effects of fatigue on people with cancer. But there is now a lot of research into this area. Things are improving and there are ways of relieving fatigue.

You are not imagining your cancer fatigue. It is very real and can have a big impact on your life. If you have symptoms of fatigue, let your doctor or nurse know. There are ways of managing fatigue and your medical team will try to help you.

Learning to manage fatigue

You can do many things in your everyday life that will help to save your energy. Taking short cuts on some things or getting help from other people may help you feel less tired.

Give yourself time

- Try not to rush – plan ahead where possible.
- Allow plenty of time for travel and avoid the rush hour if possible.

Make washing easier

Sit down to dry off after your shower, or simply put on a towelling dressing gown and let that do the work.

Have some hand rails fitted in your bathroom to hold on to when you get in and out of the shower or bath (the hospital can help to arrange this for you).

Organise your clothes

- Prepare your clothes and lay them out in one place before you dress.
- Get dressed sitting down, as far as you can.
- Try not to bend too much – rest your foot on your knee to put socks and shoes on.
- Fasten your bra at the front first and then turn it to the back.
- Wear loose fitting clothes, and things with few buttons to do up.

Sit down when you can

Where possible do household tasks sitting down – for example, peeling vegetables or washing up. You can also do ironing sitting down or buy clothes that don't need ironing.

Put chairs around the house so that you can easily stop and rest if you need to. Use a duster on a long stick and sit to do dusting.

If you have children, play games that you can do sitting or lying down like:

- reading;
- puzzles;
- board games; or
- drawing.

Avoid crowded shops

Write a shopping list and go when the shops are quiet. Ask family and friends for help with:

- shopping;
- housework; or
- collecting the children from school.

Tempt your appetite with healthy snacks

Have plenty of nutritious snacks and drinks in, so you can have something quickly and easily whenever you feel like eating.

Do things you enjoy

Don't forget to do things that you enjoy – it will take your mind off your cancer and make you feel more relaxed.

Menopausal symptoms

If you're still having periods (pre-menopausal), you might have treatment to stop your body making the hormone oestrogen. This stops your periods.

Symptoms of the menopause, such as hot flushes and sweating can be difficult to manage. Your doctor or nurse will talk this through with you, so you know what to expect. They will help you to manage the symptoms.

Feeling as well as you can

It is important that you feel as well as you possibly can. Tell your doctor or nurse about any symptoms so they can help you to control them.

About cancer pain

Pain affects people in different ways. Help is available, so tell your doctor or nurse if you have pain – even if it's mild.

Pain is usually a sign that something is wrong – that you have an illness or an injury. When there is damage to any part of your body, your nervous system sends a message along nerves to your brain. When your brain receives these messages, you feel pain. This includes pain caused by cancer.

What pain means

Having a lot of pain can be frightening. But how much pain you have isn't necessarily connected to a cancer's growth. A very small tumour that's pressing on a nerve or your spinal cord can be extremely painful. Yet a very large tumour somewhere else might not cause you any pain at all.

Some people get pain after cancer treatments like surgery or radiotherapy. Post-treatment pain like this can start or get worse after treatment. It's due to the nervous system rewiring itself after damage to the nerves. The nerves then send pain signals.

Often, this type of pain doesn't respond to ordinary painkillers. Your cancer specialist will then use other ways of treating pain.

Remember that pain might not be related to your cancer. It's completely understandable to worry about this. But sometimes pain can just be due to everyday things like arthritis, headaches, constipation or digestive problems.

With advanced cancer, between 7 and 9 out of 10 people (70 to 90%) will have pain. It is possible to relieve all pain to some extent with the right treatment. With good pain control, most people should be able to be free of pain when they are lying down or sitting.

The best way of controlling pain depends on what's causing it. The first step is to tell your doctor or specialist nurse that you have pain.

How pain affects you

Pain can affect you physically and emotionally. It's a very personal experience that feels different to everyone. What is painful and disturbing for one person might not affect someone else so much.

Everyone needs different pain treatment. What works for you might not help someone else. So having an individual treatment plan to control your pain is very important.

Try to write down as much detail as possible about your pain. This will help your cancer specialist to find out what's causing it and the best way of treating it.

Things to write down about any pain

- Where it is – in one place or spread around an area.
- What it feels like – for example, stabbing, aching or burning.
- What relieves it – for example, heat, cold, changing position, massage.
- How often you have it – always or it comes and goes.
- How it comes on – suddenly or gradually.

Supportive personnel

Specialist surgeons

Surgical oncologists are surgeons who devote most of their time to the overall management and treatment of cancerous tumours. They have the necessary knowledge, skills, and clinical experience to perform standard and extraordinary surgical procedures needed for people with cancer.

Surgical oncologists can also diagnose tumours accurately and tell the difference between benign and cancerous tumours. They understand:

- radiation oncology;
- medical oncology; and
- haematology.

Specialist medical oncologist

A medical oncologist is a specialist consultant cancer doctor who treats breast cancer patients with:

- chemotherapy;
- biological therapies; or
- other cancer-fighting drugs.

Medical oncologists may specialise in treating one or more types of cancer. The medical oncologist often coordinates the activities of a patient's multi-disciplinary team (MDT).

Oncology liaison nurses

The role of the oncology liaison nurse is to meet the needs of people with cancer including:

- psychological;
- emotional; and
- information.

The oncology liaison nurse works with you in the:

- inpatient oncology unit;
- oncology day unit; and
- throughout the hospital when you are referred to the oncology service through a consultant.

Oncology liaison nurses also provide support to families and significant others, through:

- listening;
- problem solving; and
- education.

They also:

- provide outreach support to patients at home; and
- help patients who need referral to specialist services.

Public Health and Community Nurses

A Public Health Nurse may come to your home to help you with wound care and other aspects of your treatment.

A Public Health Nurse is sometimes called a Community Nurse.

Radiation oncologist

A radiation oncologist is a doctor who prescribes radiation therapy (beams of high-energy radiation, or radioactive seed implants) to shrink or eliminate tumours. They work together with a medical physician to create an individual treatment plan for each patient.

Clinical Nurse Specialists (CNS)

Clinical Nurse Specialists (CNS) support you through your diagnosis and treatment. They:

- give you information about the disease and side effects;
- give you emotional support;
- help you to make decisions;
- assess your fitness for starting and maintaining treatment;
- are part of the multidisciplinary team looking after you;
- introduce you to the oncology liaison nurse;
- organise transport, accommodation and funding of these if you need it; and
- are always available to you and your family.

Psycho-oncologists

The psycho-oncology service is usually part of the psychological medicine service that aims to provide expert, compassionate care to patients with cancer who are attending the hospital. It aims to:

- recognise psychological distress early;
- deliver best practice in terms of interventions; and
- promote psychological well-being.

This service is available in some of the larger hospitals:

- during your diagnosis; and
- through treatment and recovery.

This service includes interventions and expertise ranging from psycho-education and self-directed learning to specific interventions. These interventions may be provided by:

- Senior Clinical Nurse Specialists;
- Principal Clinical Psychologists; and sometimes
- Consultant Psychiatrists.

Where to go for complementary therapy

When you are treated in hospital for cancer you receive what we call 'standard medical treatment'. Complementary treatments can be given along with standard treatment, but it is extremely important to make sure you have discussed this possibility with your oncologist or nurse before you plan this kind of therapy.

Many people find some of these therapies very helpful during their illness. They may help you to cope better with some of the physical side-effects of cancer and the distressing emotions that cancer can raise. Some therapies like these can also focus on spiritual healing.

These are examples of different types of complementary therapies:

- acupuncture;
- aromatherapy;
- gentle massage;
- hypnotherapy;
- meditation;
- music, art and dance therapy;
- nutrition therapy;
- reflexology;
- relaxation;
- shiatsu;
- visualisation; and
- yoga.

If you are interested in any of these complementary therapies, do speak to your oncologist first. Many of these therapies will be on offer in your local cancer support centres. Alternatively, you can speak to your GP who can provide a contact for you.

You will very likely need a supporting letter from your oncologist to receive this treatment. You will also receive a full assessment from a health professional at the support centre to make sure you are getting the right type of therapy for you. See a list of cancer support centres in this booklet.

Palliative care specialists

Some people find it frightening to talk about palliative care because they fear that this means they are nearing the very end of life.

However, palliative care specialists can help you from a much earlier stage so that you can have a better quality of life.

A palliative care specialist can help to relieve pain and other troubling symptoms and meet your needs:

- emotional;
- spiritual, and
- practical.

Counselling organisations

Coping with a diagnosis of cancer can be very difficult and stressful on you and your family. A cancer diagnosis will change how you think about things and life itself will change. Sometimes it is hard to come to terms with your diagnosis and you and your family will have some reactions which are very common and normal. These emotions may include:

- shock and disbelief;
- denial;
- withdrawal and isolation;
- fear of dying;
- anger;
- loss of control;
- resentment;
- sorrow and sadness; and
- blame and guilt.

It may be difficult for you to come to terms with these feelings and emotions. You may even find it difficult to talk to close friends or relatives. It is therefore important for you to recognise this and ask for help. Counselling can provide you with the emotional support you need in a professional and confidential place.

If you feel that counselling is something you or a member of your family may need, do speak to your oncologist first. There are many qualified counsellors available in your local cancer support centres. Alternatively, you can speak to your GP who can provide a contact for you.

You or any member of your family will receive a full assessment from a health professional or counsellor at the support centre to make sure you are getting the right type of support for you and your family.

There is more information on 'Feelings and emotions' later in this booklet.

Your emotions and cancer

There's no right or wrong

You may find that you have different feelings from other people with cancer. When you are trying to come to terms with an illness there is no right or wrong way to feel. Everyone is different, and you will deal with things in your own way. So take what you need to help you from this section and ignore anything that doesn't seem to apply to you or to help.

How you may feel when you are diagnosed

Being diagnosed with advanced breast cancer is likely to bring up many emotions. Most people feel shocked and don't know what to think. You may be confused, upset and worried.

Shock

Shock is often the first reaction when a doctor tells you, you have advanced breast cancer. You may:

- feel numb;
- not believe what is happening;
- be unable to express any emotion;
- find that you can only take in small amounts of information; and
- need to have the same information repeated to you.

Needing to have information repeated is a common reaction to shock. You just can't take anything in at first.

Your disbelief may be so strong that you find it difficult to talk about your illness with your family and friends. Or you may find that you need to talk about it over and over again to help the news to sink in.

At times, it may feel like an emotional roller coaster. One day you might be quite positive and able to cope. But the next day you could feel so sad and anxious that coping might not seem so easy. All these feelings are completely natural.

Denial

Some people choose to cope with their situation by pretending it's not happening. It's not that this is necessarily a conscious decision. It can be a gut reaction. You may just feel overwhelmingly that you can't think about it whenever anyone brings the subject up. You may find that you:

- don't want to know anything about your cancer or treatment; or
- prefer to talk about it as little as possible or not at all.

This is another completely natural reaction. If you feel this way, you can tell the people around you quite firmly that, for the time being, you don't want to talk about your illness.

But in extreme cases, denial can be unhelpful. Some people deny their cancer so firmly that they convince themselves that either they aren't ill at all, or that their illness isn't cancer. If this reaction starts to get in the way of your treatment or makes your overall situation even worse, you may need professional help from a psychologist or counsellor.

Other people being in denial

Sometimes you may find denial happens the other way around. You may need to talk about your cancer, but your family and friends may be the ones in denial. They may:

- try to dismiss the fact that you are ill;
- seem to ignore the fact that you have cancer;
- play down your anxieties and symptoms; or
- deliberately change the subject.

People can react in this way because they are frightened of cancer themselves. They may be embarrassed by talking about it. Or they may be terrified that someone they love has a life-threatening condition.

They may avoid talking about it so they can pretend it isn't happening.

But if you want their support, and to share how you feel with them, this behaviour may hurt or upset you. If you feel like this, try to:

- tell them how you feel;
- reassure them that you know what is happening; and
- explain that talking to them about your illness will help you.

If you are a friend or relative

Relatives and friends can help by listening carefully to everything the person with cancer says; and not rushing into talking about the illness.

Sometimes it is enough just to listen, letting the person with cancer talk when they are ready. Take your cues from the person. If they get upset, that is OK. It can be a relief for them to be able to cry and say if they are finding things difficult.

Your emotions during treatment

People diagnosed with cancer and going through treatment often feel negative. At times, you may think you will never feel well again. Many questions may arise, such as:

- will I ever feel happy again?
- when am I going to die?
- why has this happened to me?

You may also ask yourself if you will be able to get yourself together and enjoy the things that you used to – even your husband or children can't seem to make you feel happy any more. People may tell you, you must be positive – and you may ask 'am I harming myself when I feel so low?' All these thoughts, feelings and questions are very natural and completely understandable.

Your family and friends may expect you to feel back to normal in-between treatments. But many people with cancer find that this is the time when the emotional impact of their diagnosis hits them and they need more support. You may miss the support from the doctors and nurses at the hospital. When your cancer is very advanced, and you are facing the possibility of dying, all these feelings are likely to be more intense. They will take on a different meaning.

Understanding your feelings

Having negative feelings can be very draining for you and the people around you. You might find that family and friends don't understand. Or they may try to tell you how you should feel. This can put a big strain on your close relationships.

Asking for help

Talking about your situation really can help. If you would like to share your feelings with someone, but don't feel you're able to talk to your friends and family, it may help to talk to a counsellor.

Don't feel you are being weak by asking for help or letting someone know how awful you feel. It is not a weakness. Talking about how you feel is more likely to help you and the people around you than staying silent.

Doctors and nurses in cancer care are very aware of the range of reactions people can have to cancer. There may also be counsellors or psychologists in the cancer team at your centre. They can help you through difficult, emotional times after your diagnosis and during treatment.

They will be ready to listen to you, give you support, and suggest ways to help you feel more positive about things.

It is also worth finding out what support is available at your local hospice. Many hospices offer all sorts of help to people with advanced cancer including:

- complementary therapies;
- counselling; and
- short stays to give you and your family a break (respite care).

Support outside the family

If you would like to talk to someone outside your own friends and family, look at our list of counselling organisations.

Evelyn Wakefield tells us about living with advanced breast cancer

Evelyn Wakefield was 33 when she was diagnosed with advanced breast cancer, lives near Birr in Co Offaly and is married with two children

Evelyn Wakefield was diagnosed with ‘de novo’ breast cancer in June 2015. First, she was told she had breast cancer, then two weeks later she was told it was advanced breast cancer and could not be cured. When someone is found to have advanced breast cancer at their first diagnosis, it is called ‘de novo’.

“You are kind of left with that and told to go home. I envisaged chemo, losing my hair and being a sick, pale, unhealthy woman sitting in a chair in the corner of my living room being almost unable to lift a cup. But it is very different to that,” says Evelyn.

“Initially I went into panic mode. I thought, I have two young children and I am not going to see any of their lives. Evelyn was 33 when she was diagnosed. At the time her two children were 3 and 9 years old.

“If I had met someone when I was diagnosed, who looked as well as I did a few weeks ago and was told they were 3 or 4 years gone, I would have gone ‘And that person has cancer?’.

“Yes, it is a hard road at times, but you function pretty well in-between the bad times. That was something I never ever thought I would be able to do,” says Evelyn.

“There was a history of breast cancer in our family, but when I found the lump initially I wasn't even going to go to the GP. Then I decided to err on the side of caution. That was lucky in one sense but unlucky because it had already spread. I didn't realise it could spread so quickly.

“When I was diagnosed, I would have liked to have known that you can live well with it for quite a while. You can do your ordinary day-to-day things. I succeeded in working until September 2016.

Fatigue

“Fatigue has always been my biggest side effect. I go from being grand to being panned out in 0.3 seconds.

“I don't think you can understand the fatigue until you have actually gone through it. My best description is when you are really tired and pregnant, multiply that by 50 and you might be close to it. It's just complete exhaustion, your body just won't stay going. You have no choice but to give into it.

“You can learn to balance your life and incorporate your illness and your appointments into your life, it kind of becomes the new normal. I don't know when I am going to be extremely tired, so how do I plan for that day? The palliative care nurse said the thing to do is that when you feel okay, make the extra lasagne and throw it in the freezer so the day you get up and you are actually not able to do anything, things are nearly already in place.

“I found that very difficult in the beginning because I was always a doer and I did everything myself. As far as the kids were concerned I worked my job around the kids so they always had access to their activities and so on. I found it very hard to ask for help and to ask others to take the kids,” says Evelyn.

Conserve your energy

“I think that is a big thing from a young mother’s point of view. People say they will do anything for you, but unless you ask they actually won’t. It is not until you are in the midst of it that you realise, I can’t actually take the child to training tonight.

“You need to learn to get someone to take them to training and conserve your energy for the match. I tried to get people to do the in-between stuff so that I am well enough for the school concert or the match or whatever – for the big things in their lives,” says Evelyn.

Keep home life simple

“I just keep everything at home quite simple. We do things like camping out in the back garden. We cook marshmallows. We had snow here the first year I was sick and we got up at half 5 and went out sledging with the kids. I was like ‘I may never see the snow again, so let’s do this this morning. I can recover afterwards’. By the time the kids came home from school, the snow was gone.

“You just do have to do the important things as they come up and don’t wait for the next day. Because the next day isn’t certain,” says Evelyn.

Adapt your house to your needs

“You have to adapt your house and your lifestyle. For me because the cancer is also in my back, I had to give in and get a hospital bed at home. I need to lie with my legs raised and my back raised. I also got a reclining chair. And a chair for the shower. A perch stool for the kitchen. I also had to get a raised seat for around the toilet to lift myself up, for when my legs would be weak at night.

“I can now sit in the sitting room comfortably for the evening. And when I go to bed I can get a proper night's sleep, rather than being up half the night in pain. By allowing those things into the house it makes family life easier. The message I always try to convey to people is take help, ask a friend to do the school run.

“Forget about the housework. The house will be there. The kids are not going to remember if the floors are clean or not, but they will remember if you read the story with them or not,” says Evelyn.

Dealing with chemotherapy

Evelyn has had several courses of chemotherapy.

“I firmly believe that after this bout of treatment, in a few months I will pick up again and go again for another couple of years. There are new drugs coming out all the time. It's about prolonging your life for as long as you can. In between treatments, I have been quite well and I have done things that before I was diagnosed I would never have thought were possible. We've gone to Disneyland with the kids and on a trip to Canada.

Keep a diary of symptoms, medication and treatment

Evelyn advises people with advanced breast cancer to keep a diary and put absolutely everything in it:

- any questions you have
- how you feel;
- how tired you are;
- how much pain you have;
- where the pain is; and
- what type of pain (dull, sharp, ache).

“You go into a consultation and you think you will remember, but you won’t. This diary will be your bible through everything. If I feel I have had a bad week, I can look back and say, ‘do you know what now, it wasn’t as bad as I thought’. Or ‘Oh crap it is as bad as I thought. I can’t continue like this, so I need now to ring someone’.

“If you are having a bad day and maybe sleeping a lot, the diary will tell others what medication you are on. It is a good idea if even though you manage your own medication, someone else also knows how to check on it – in case you feel too ill. If you are very sleepy, you need to make sure that you don’t get dehydrated, as the medication you take may then become toxic.

“I would also advise people to keep a copy of all their scan results. So that when you come home you read over them, you are happy that they compare. If you’re not happy you can go back and ask questions.

“Always be prepared for your consultation as they are very short. It helps to find the key points in your diary: how much pain you had; is this normal? Should it be treated? Be very clear on how you are feeling.

“Don't be afraid to ask questions. No question is a stupid question. Write your questions down and bring them with you,” says Evelyn.

Talking to friends and family

“Talk to your family and to your friends. I know a woman who hasn't even told her family she is at stage 4. She doesn't want the pity. ‘They know I've got cancer, but they don't know it's going to kill me,’ she told me,” says Evelyn.

When telling her family Evelyn was very candid.

“I just said ‘This is crap, and we're going to have to make the best of it’. As far as telling the kids I firmly believe in telling them sooner rather than later. I don't believe in keeping it from them – they know there's something wrong. I think you create fear by not telling them. I told the kids quite early on. I didn't tell them it would eventually kill me. But my older son knows that now. I just told them that it was serious and it would never go away.”

Evelyn uses resources at <https://www.kidskonnected.org/> when talking to her children about her illness.

Evelyn advises that when you tell people about your illness make sure they understand it is your news to tell and you don't want them telling everyone about your illness.

Friends and family can find it difficult to talk about the illness especially when she asks, "What if this is the beginning of the end?". It is helpful when friends and family ask, "How are things today?", not "How are you?".

Evelyn has found it helpful to go, along with her husband, to a professional psycho-oncology counsellor. Evelyn also attends the Marie Keating Foundation monthly meetings for women of her age group who have cancer.

Evelyn is also involved with Europa Donna Ireland. Europa Donna is an Irish breast cancer campaign group. It is one of 47 Europa Donna member countries across Europe. Europa Donna Ireland is a volunteer-run organisation whose membership is largely made up of people with experience of breast cancer. It is a registered charity.

Make a will

"When I was diagnosed, we had no will made. It is important for people to remember to do that. I made it clear to my family that I wanted the funeral we want to be honoured. That can be a hard conversation to have. I want my husband's decisions honoured. You should have this conversation sooner rather than later because you just don't know. Everyone lives with uncertainty, but with metastatic breast cancer it's a greater uncertainty," says Evelyn.

Diet and nutrition

Good nutrition is important during your cancer journey. However, the cancer itself and its treatment can mean that the pleasure you once got from eating is lost. That can also mean that you lose weight. Weight loss can have a big impact on your quality of life and can also have a negative impact on your treatment, making it more difficult to tolerate some types of therapies like chemotherapy. Keeping well-nourished is also good for your overall physical and mental well-being.

It is always a good idea to speak to a dietitian about your own specific dietary needs when you are on treatment. Dietitians can assess your weight and height and look at your blood test results to help them decide what dietary advice to offer you.

If you are losing weight, try to eat meals that are palatable and high in calories and protein. University College Cork and Breakthrough Cancer Research have put together a cookbook with recipes like this called 'Good nutrition for cancer recovery'. You can order it online at: www.breakthroughcancerresearch.ie/good-nutrition

Poor appetite

If your appetite is poor, try to eat small amounts whenever you can. Eat whenever you feel hungry. If you feel hungriest in the morning, then eat your biggest meal at this time.

Eating small meals or snacks throughout the day, varying your diet and making meals into social events may help improve your appetite and make eating more enjoyable.

General diet tips

Not everyone has eating or weight problems during or after treatment. If you are otherwise feeling well, try to eat a variety of healthy, unprocessed foods so that you maintain strength and energy.

Fruit and veg

Try to eat a diet that is plant based – eat as many fruit and vegetables as you can.

Anti-inflammatory

Inflammation is part of the body’s immune response; without it, we can’t heal. But when it’s out of control, it can damage the body. It is thought to play a role in obesity, heart disease, and cancer.

Foods known to have anti-inflammatory properties				
Tomatoes				
Olive oil				
Green leafy vegetables including	spinach	kale		
Nuts including	almonds	walnuts		
Fatty fish including	salmon	mackerel	tuna	sardines
Fruits including	strawberries	blueberries	cherries	oranges

Foods known to be inflammatory are refined carbohydrates

White bread and pastries

Fried foods including

Chips and
French fries

Other fried foods

Fizzy drinks

Red meat including

burgers

steaks

Processed meat including

hot dogs

sausages

Margarine

Lard

Use herbs and spices

Many herbs and spices are rich in phyto-nutrients, also called phyto-chemicals, which are chemicals produced by plants. These are not essential for keeping you alive the way that vitamins and minerals are, but they can improve your health.

Among the benefits of phyto-nutrients are antioxidant and anti-inflammatory properties. Phyto-nutrients may also:

- enhance immunity and intercellular communication;
- repair DNA damage from exposure to toxins;
- detoxify carcinogens; and
- alter oestrogen metabolism.

Phyto-chemicals are best taken in by eating the foods that contain them rather than taking supplements or pills. Other foods that are rich in phyto-nutrients include:

- colourful fruits;
- peanuts;
- green vegetables;
- legumes, like lentils and split peas;
- nuts;
- tea; and
- whole grains.

Avoid processed food

Processed foods are linked with cancer including:

- ham;
- sausages and burgers; and
- those high in fat like French fries and cakes.

The more whole, unprocessed foods you can eat, the better.

Food hygiene

When you have cancer, it is important to take special care with food to avoid infections as some cancer treatments make you more vulnerable to infections. Take special care when handling and preparing food.

Here are some tips.

Keep food preparation area clean

- Wash your hands, knives, and counter tops before and after you prepare food.

This is most important when preparing raw meat, chicken, turkey, and fish.

- Use one cutting board for meat and a separate one for fruits and vegetables.
- Thoroughly wash all cutting boards as well as utensils and your hands between handling raw and cooked foods.

Watch food temperature

- Keep hot foods hot and cold foods cold.
- Put leftovers in the refrigerator as soon as you are done eating.
- Always thaw frozen foods like meat in the fridge or defrost them in the microwave – do not leave them sitting out.
- Do not refreeze food once you have defrosted it.
- Cook meat, chicken, turkey, and eggs thoroughly.
- Meats should not have any pink inside.
- Eggs should be hard, not runny.
- Do not eat foods that show signs of mould – this includes mouldy cheeses like blue cheese.

Clean fruits and vegetables

- Scrub all raw fruits and vegetables before you eat them.
- Boil berries before eating them as they cannot be scrubbed.
- Always wash pre-packed fruit and vegetables, even if the pack is marked 'pre-washed'.

Avoid raw fish

Do not eat raw fish or shellfish, such as sushi and uncooked oysters.

Stick to sell-by dates

Check 'use by' and 'sell by' dates and do not use foods that are out of date.

Be careful when eating out

Do not eat at:

- buffets;
- salad bars; or
- self-service restaurants.

Exercise when living with advanced cancer

Physical activity and exercise provide a wide range of benefits to people diagnosed with breast cancer. The benefits include improved physical fitness, higher self-esteem and lower levels of anxiety, depression and fatigue. Any level of activity that you feel able to do and you like doing is good, even gentle exercise. It is advisable to consult with a physiotherapist before you start exercising.

The following are some things to consider before you start;

1. Doing any form of exercise, whether this is walking or using a bike (machine) or balance exercises can benefit your physical and mental well-being.
2. Know what your limitations are and the location of where your cancer has spread. For example, if you have bone metastases know exactly where these are so you can take precautions to limit damage to this part of the body. E.g. if there is metastasis in the spine it is advisable not to do any rotation, so keep the spine in alignment.

3. Manage your symptoms where possible to enable physical activity, e.g. take analgesics to control pain, unfortunately with nausea it is more difficult to exercise with this symptom. If you suffer from neuropathy stable exercise is better, like a bike/rowing machine. Exercise can help with fatigue, like stretching & walking.

4. If you suffer from breathlessness, it might be worth your while asking for a referral to a Physiotherapist to get assessed, as it needs to be determined whether your breathlessness is 'normal'. People are often concerned about becoming breathless when they exercise, but this is normal. However, it may be the case if you have not been able to do any activity your tolerance for activity will be limited, so you may experience breathlessness on minimal exertion, so you are advised to just start slowly to build up your tolerance again.

Avoiding and managing lymphoedema

Physical activity and exercise provide a wide range of benefits to people with advanced breast cancer. The benefits include:

- improved physical fitness;
- higher self-esteem; and
- lower levels of anxiety, depression and fatigue.

How you can help prevent lymphoedema

What is lymphoedema?

Lymphoedema is an accumulation of lymph fluid in the soft tissues of the arm, chest or trunk, with accompanying swelling in these areas. This accumulation of fluid is due to a disruption in the lymphatic system which may be due to:

- surgery;
- node clearances; and, or
- radiotherapy.

It is important to follow these guidelines if:

- you have had surgery on the nodes – ‘axillary clearance’ or ‘sentinel node biopsies’; and
- you have or may have radiotherapy after your surgery.

This will help you to prevent developing complications like infection or lymphoedema. Prevention is the best tool against the development of lymphoedema.

What are the signs and symptoms of lymphoedema?

Swelling in one or all of the following:

- fingers;
- hand;
- arm; and, or
- upper trunk or chest.

Other signs of lymphoedema include:

- sensation of heaviness, fullness in the arm;
- feelings of soreness or discomfort in the arm and shoulder;
- skin harder than usual, less soft or less supple;
- loss of movement in the joints of the arm; and
- watch or rings becoming too tight.

This list is not exhaustive, and these symptoms can appear at any time after the surgery, or during or after your radiotherapy treatment for years after the surgery.

Can I get physiotherapy to treat lymphoedema?

If the breast care team or your physiotherapist feels you are developing signs of lymphoedema, they will refer you to a senior physiotherapist specialising in the area. The physiotherapy approach will consist of many different treatment options.

Some of these may include:

- manual lymphatic drainage;
- exercises;
- intermittent pneumatic compression;
- compression sleeve garments;
- multi-layered bandaging of your arm; and
- skin-care and prevention advice.

You may have concerns about, or feel you are developing any of the mentioned symptoms. If so, please contact the physiotherapy department or your breast care team:

- for further advice and information;
- to be referred to the Lymphoedema Clinic; or
- both.

What can I do to prevent lymphoedema?

Due to the lymphatic system being impaired following surgery, you should take precautions. Even minor injuries such as scratches, cuts or burns can provide an entry site for infection. Treat these immediately by cleaning and applying an antiseptic.

Important

If your wound becomes red, hot, swollen or painful or if you feel unwell, contact your GP or the breast care nurse.

Don't overdo it

- Avoid using your affected arm for heavy lifting or heavy housework for four weeks.
- Do not lift anything heavier than a full kettle.
- Activities such as ironing or hanging out washing can be done if pain free.

Protect the affected side

- Do not have injections, blood samples or your blood pressure taken on the affected side.
- Wear gloves and long sleeves to avoid scratches when gardening.
- Wear a thimble when sewing.
- Wear oven gloves to take items from the oven or lifting hot pots to prevent burns.

Avoid extreme temperatures

- Protect yourself from sunburn.
- Avoid very hot baths, saunas or extremes of hot and cold.

Mind your cuticles

- Don't cut cuticles on the affected side.
- Keep your skin and cuticles well moisturised to avoid dry skin.

Be careful what you wear

Avoid wearing restrictive clothing or jewellery on the affected side.

Protect against insect bites

If you are in an area where you might expect insect bites, use insect repellent or cover up to reduce exposure.

Avoid wet shaving

As cuts increase the risk of infection, avoid using wet razors to remove unwanted hair. Use an electric razor or depilatory cream.

Flying

It is recommended that you wear a compression sleeve when flying. You can contact the physiotherapy department if you need a sleeve.

Driving

Check with your doctor. Only begin driving when you feel comfortable to do so. You may need to check with your insurance company.

Body image, sex and identity

Breast cancer can affect a woman's sense of herself. You may be dealing with:

- having had a mastectomy;
- metastases, particularly in the brain; and, or
- losing your hair.

These can all be a signal to the world that 'I have cancer'. You may feel people are looking at you and making a judgement about you.

If you have had cranial radiotherapy and needed to take steroids this can further change the image. Your face may not be similar to what it was before. You can look at pictures of you a couple years ago and now, and they look very different. That can be very upsetting for a person because it makes them feel that they are no longer like themselves.

When giving you your medical treatment, the healthcare team will try to give you back control. You do have choices you can make, but people can feel very disempowered. In addition:

- if you have liver metastases, energy can be a problem;
- if you have bone metastases, pain can be an issue; and
- depending on where in your body you have cancer, mobility can be an issue.

That is where the physiotherapist or occupational therapist can help with some aids or adaptations that can really help you to continue to maintain your independence.

Cancer and sexuality

Having advanced breast cancer can be very confusing and difficult to cope with. It can sometimes make it difficult to respond to your partner during sexual activity. It's important to remember that everyone is different. There is no right or wrong way to feel about your sexuality and sex life. How you feel sexually can change. You can work on changing this and finding new ways to communicate your feelings to your loved ones.

Things that may change sexual responses

Many things can change how your body reacts during sexual activity. They can include:

- tiredness (fatigue);
- feeling sick;
- pain;
- bowel problems due to cancer treatment;
- surgery or radiotherapy to your breasts, or to your pelvic or genital area;
- hormone imbalances in the body; and
- problems with the nerves or blood vessels in your pelvic area.

Your state of mind can also change your sexual response if you are:

- depressed;
- stressed;
- afraid;
- angry; or
- anxious.

It can also affect your sexual response if you are feeling unhappy with changes to your body caused by cancer or its treatment.

Side effects can also change how you feel about sex. This includes side effects from certain drugs like:

- chemotherapy;
- blood pressure drugs;
- alcohol;
- nicotine;
- painkillers; and
- anti-nausea drugs.

You may also be stressed by:

- financial worries;
- work; and
- relationship difficulties;

Many of these problems can happen when you have cancer, which can mean that you're less likely to enjoy or want to have sex. This can be hard to cope with.

Talking about your sexuality and sex life

Some people find it difficult to talk about their sexuality and sex life. Cancer and treatment may mean that you cannot have sex or do not feel like it. These issues are very private. But if you have any worries it can help to talk to a close friend or your partner about them.

If you are in a relationship and try to keep your concerns to yourself, your behaviour may confuse your partner. They may feel rejected, or think that you no longer love them or feel attracted to them.

If you and your partner stop having sex it often affects other types of intimacy. You might avoid hugging and kissing because you worry that it could arouse your partner and then upset them because you don't want to go on and have sex.

Sometimes people with cancer avoid physical contact with their partner because they are unhappy with changes to their body.

Feeling less confident about sex

If you are single you might avoid getting into a relationship as a result. Any changes in your appearance or physical ability to have sex might make you feel less confident about sex. For example, if you had a breast removed or have scarring.

If you are able to talk to your partner about your worries, you will both gradually get used to your new situation and things will feel less awkward. A caring and loving partner can help to ease your concerns. You might also find it helpful to talk to your doctor or nurse about how you are feeling. They might suggest that you and your partner have some counselling to support you through this difficult time.

If you are single and worried about your sexuality it might also help to talk to a close friend or counsellor about how you are feeling.

Coping with the financial implications of cancer

Benefits for people who are sick or have a disability

There are a number of social welfare payments for people who are sick or who have a disability. Payments are made either by the Department of Social Protection or the Health Service Executive (HSE). To qualify for a social welfare payment because you are sick or have a disability you must be certified as sick or disabled by a doctor.

You can qualify for certain payments if you are sick for just a short time. For other payments you need to show that you have an illness or disability that will last longer than one year. Some social welfare disability payments are based on your PRSI contributions. If you do not have enough PRSI contributions you may qualify for a similar social assistance payment, however, you must pass a means test.

- Illness Benefit is intended for those with a short-term illness.
- Invalidity Pension is a long-term payment.

Illness Benefit and Invalidity Pension are both social insurance payments based on your PRSI contributions.

Disability Allowance

This is a long-term social assistance payment for those aged 16-65 with a disability expected to last at least one year.

Supplementary Welfare Allowance

If you are sick and do not qualify for any payment you may be eligible for Supplementary Welfare Allowance.

Generally, social welfare payments are made up of a personal payment for yourself and extra amounts for your dependent spouse, civil partner or cohabitant and your dependent children.

Other payments

If you are getting a social welfare payment you may qualify for additional financial support because of your illness or disability, for example, under the Supplementary Welfare Allowance Scheme you can apply for a Heating Supplement, if you have exceptional heating expenses due to ill-health or infirmity. You may also be eligible for:

- the Long-Term Illness Scheme;
- a Medical Card; or
- a GP Visit Card.

Apply to your Local Health Office in the Health Service Executive.

Driving and home benefits

There are concessions for disabled drivers and passengers and local authority grants to adapt your home.

Tax benefits

There are also tax benefits available to people that are sick or have a disability.

Carer's payment

If someone is providing you with full-time care they may qualify for a carer's payment.

Medical card application form

You can apply for a Medical Card online at:

- www.hse.ie/eng/cards-schemes/medical-card/

Your illness may mean you are entitled to a Medical Card. People who hold a Medical Card are entitled to a range of Health Services free of charge.

Call the HSE customer care team at the Client Registration office on Call Save 1890 252 919 for any other questions you have about Medical Cards. They can also post an application form to you, or help you in filling in the form or making your application.

Non-Medical Card holders

Everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is an €80 a night charge up to a limit of €800 in a 12-month period. Higher rates apply for semi-private or private care.

You may be entitled to some community care and personal social services.

Mortgages, loans, pensions and insurance

Mortgages and loans

You may be experiencing payment difficulties with your mortgage, due to your illness, and you may be worried about losing your home. Talk to your lender. If you can't, talk to MABS (Money Advice and Budgeting Service), the state money advice service.

MABS now has a dedicated confidential, free, and independent mortgage arrears service. It is a state-funded service for mortgage debt advice and referral. You can call MABS on 0761 07 2000 for independent information, advice and referral.

Loans

If you are unable to make payments on other loans you can contact MABS for help on this too. It is the same phone number 0761 07 2000.

You can also send an email to helpline@mabs.ie if you have any queries. MABS does not offer financial advice on investments or on specific financial products. Remember that MABS also does not give out money, if you are in need of it.

Pensions

You may be worried about continuing to pay into a private or occupational pension scheme. You will need to contact the trustees in an occupational (workplace) pension scheme; and the provider in a private scheme. They will tell you how this may affect your pension provision for you or your loved ones.

Health insurance

If you have advanced breast cancer and you have private health insurance, before you attend hospital check with your provider what cover you have for inpatient and outpatient services.

Prostheses, bras and appliances

For patients who have Medical Cards, most appliances are free of charge or subsidised. If you have had a mastectomy you are entitled to a first prosthesis and two mastectomy bras free of charge. This rule applies to all women. If you qualify for a Medical Card, you are entitled to one prosthesis every two years and two mastectomy bras annually.

Medical card holders require a prescription from a nurse or GP. This is sent to your local Health Centre who will then send you a Purchase Order. The Purchase Order must be taken to the company authorised by the HSE to supply prostheses and mastectomy bras on their behalf.

You may also be entitled to mobility aids and 1–2 free or subsidised wigs or hairpieces every year.

The Drugs Payment Scheme also covers the cost of some appliances. If you have private health insurance, some policies will reimburse you for your appliances, for example breast prostheses, every year but you must have spent over your minimum requirement to make an outpatient claim.

Other insurance policies will cover a percentage of your prostheses costs. Do check your insurance policy to find out what is covered and how you should submit claims.

Coping with the financial implications of cancer

You can also claim tax relief on any medical purchases like prostheses and wigs.

The criteria to determine whether or not you receive a Medical Card – or other medical financial assistance – can vary from one HSE region to another.

Financial implications: useful contacts

	Phone	Website
Medical cards	Phone HSE customer care team. Call save 1890 252 919	www.hse.ie/eng/cards-schemes/medical-card/
Free advice Money Advice and Budgeting Service, MABS	0761-07 2000	www.mabs.ie;
Citizens' Information Service	0761-07 4000	www.citizensinformation.ie/en/

Making the most of every day

Marie Keating Foundation Positive Living programme

Being diagnosed with advanced cancer can be an emotional time that can lead you to have many fears and questions and moments of anger and confusion. At a time where you need the most support, some people with advanced cancer can find that it is very hard to find.

The Marie Keating Foundation set up a Positive Living programme to support people with advanced cancer, who have their own emotional, physical, and practical needs separate to other cancer patients.

This programme includes free, six-week courses and meetings that are led by local experts that provide resources and support to help people with advanced cancer to navigate through their specific needs.

Common themes explored in the programme include:

- working with your medical team and managing side effects;
- coping with the emotional impact of advanced cancer;
- sexuality and relationships;
- altered body image, positive appearance and well-being;
- using mindfulness to cope; and
- physical activity and stress management.

The aim of the programme is to help people who have advanced cancer to improve their quality of life. We provide specialised supports and connect you with experts in your local community. We also connect you with other people affected by similar circumstances who you may be able to relate to on a peer-to-peer level. It is hoped that through the course, you will be able to look ahead and plan for the future.

All courses and seminars are free to attend, but places are limited and registration is essential.

If you would like to apply for an upcoming course or seminar, please contact Angela Egan, the Marie Keating Foundation, on 01 628 3726 or email info@mariekeating.ie. Please say which course or seminar you are applying for.

Marie Keating Foundation Positive Living courses

Phone: 01-628 3726

Email. info@mariekeating.ie

Europa Donna Ireland

Europa Donna Ireland runs a peer-to-peer support network for women living with advanced breast cancer. It is called Connect MBC (metastatic breast cancer) Network. They also run free events open to those with advanced/metastatic breast cancer and to members of their family and friends.

According to Tara Byrne of Europa Donna Ireland, advanced breast cancer is increasingly being seen by the medical profession as a chronic disease.

“As many as 1,500 to 2,000 people in Ireland are living with advanced breast cancer at any one time. But, despite these figures, there continues to be widespread misconceptions and misunderstandings about the disease.

“The experiences and the knowledge of those living with this incurable disease are rarely spoken about. This is a situation that compounds the sense of isolation and hopelessness felt by many.

‘Connect MBC Network’ builds a safe online community where people with advanced/metastatic breast cancer can connect with each other to find support, share experiences and learn more about their disease,” says Ms Byrne.

For more information see <http://www.europadonnaireland.ie>

Plurabelle Paddlers

Europa Donna is also behind setting up Plurabelle Paddlers. Plurabelle Paddlers is a dragon-boat team based in the Grand Canal Dock in Dublin, Ireland. Dragon boating is a team water-sport that originated in China centuries ago

The Plurabelle team members have one thing in common, they have been diagnosed with breast cancer and have set up a dragon-boat team to:

- get fit;
- enjoy the mutual support of team mates; and
- raise awareness of breast cancer.

They are all new to the sport and are inspired by the 150 or so breast cancer dragon-boat teams worldwide.

Why dragon boats?

Dr Don McKenzie, a sports medicine physician at the University of British Columbia, Canada, ran a study to test the theory that repetitive upper-body exercise in those treated for breast cancer could prevent lymphoedema, a chronic swelling of the arm.

Dr McKenzie believed that by following a special exercise and dragon-boat training program, people could avoid lymphoedema and enjoy active, full lives. The initial group was carefully monitored and no new cases of lymphoedema occurred and none of the existing cases became worse.

This inspired those in the study to form the first breast cancer dragon-boat team Abreast in a Boat, the sport now has now grown to more than 150 breast cancer teams worldwide. The Plurabelle Paddlers is the first team in Ireland.

The team was set up by Fiona Tiernan to keep fit after a recurrence of breast cancer. From a membership of two and no boat in 2010, it now has more than 60 active members, a wonderful coach Julie Doyle and two dragon boats.

The team trains on the water twice a week from March to November, and once a week during the rest of the year. It has members aged from early 30s to more than 70.

The other thing they all have in common is that they were all new to the sport of dragon-boat racing when they began.

For more information see: <http://www.plurabellepaddlers.com/>

Coping psychologically with terminal illness

The emotional experience during cancer is highlighted in a PHD study carried out by Counselling Psychologist, Dr Sinéad Lynch

Dr Sinead Lynch worked with 12 people with cancer to find out how they treated themselves and coped with their cancer. She found that most people did not accept that they were traumatised because of the cancer.

“They had this ‘I just need to cop on’ frame of mind. Or they were harsh on themselves. They’d say, ‘Stop feeling sorry for yourself, there is no point feeling like this’.

“Half the participants would feel self-blame for bringing the illness into the lives of their family. They felt guilt on a daily basis and were harsh self-critics telling themselves: ‘You’re not handling your emotions right – you need to get on with this’,” says Dr Lynch.

Dr Lynch is a counselling psychologist and a qualified counsellor and psychotherapist working in South Dublin.

Self-compassion is more than ice-cream in bed

When we talk about self-compassion and self-kindness, it is not necessarily just the Ben and Jerry’s ice-cream in bed. Self-kindness and self-compassion are not self-pity.

Interview: Coping psychologically with terminal illness

When you are self-pitying, you are just looking down on yourself – think of yourself as stomping on a plant. Whereas self-compassion is nurturing yourself and being aware of that inner voice. That voice that is either telling you to ‘cop on’ or else is talking to you in a loving way like someone who loves you would talk to you.

Show yourself compassion

“It is good to show yourself compassion, but it is even more important to practise self-kindness. Be careful of those voices in your head saying: ‘You need to cop on and don’t be feeling so sorry for yourself’ – that is not as helpful as we may think,” says Dr Lynch.

Self-compassion is not self-pity, it is noticing when you are being too tough on yourself. If you are telling yourself to ‘Cop on, get on with it, stop feeling sorry for yourself’ when you are having a really tough day, it can affect you negatively.

“You need to be kind to yourself on the days when perhaps you’ve had chemo, you’ve tried to look after your kids, and your husband comes in tired from work,” says Dr Lynch.

“Try and treat yourself like you would someone else you loved. You wouldn’t say to them: ‘Would you ever cop on!’. You’d say: ‘God I know it’s so hard’, and you’d probably give them a hug,” says Dr Lynch.

Mindfulness can be useful

Mindfulness and self-compassion are different although self-compassion can be part of mindfulness. Self-compassion and

mindfulness mean that you allow something to be whatever it is with no judgement.

“If ‘It is shit’, which is what people often say, you just allow the ‘shit’. You are just allowing how bad this is just now. It doesn’t mean I am happy about it, I do want it to change, but if I just allow it and I don’t fight it, it will change, because nothing is permanent. Everything changes,” says Dr Lynch.

With advanced breast cancer, mindfulness can help you get the most from each day.

“If you allow your mind to always go into the future and think ‘Well I’m going to be dead of this disease in a year’s time’ then you are always going to feel bad.

“Our thoughts can really impact our emotions. So, if my thought is always that I’m going to die next year, my emotions are going to be pretty bad. But that thing hasn’t happened yet, you’re not dead and we will all die,” said Dr Lynch.

Sharing feelings and emotions with loved ones

Nearly everyone in this study said they didn’t want to burden loved ones by telling them how they felt. When they did tell people, they felt there was a limit to how much they could say. They’d feel:

- ‘I’ve already told them how bad I feel, and they don’t want to listen any more’; or
- ‘I can’t be burdening my children even though they’re adult – I don’t want to worry them – I don’t want to worry my spouse.’

People with cancer are often thinking about the other person

“It is understandable that when you go through cancer you mightn’t want to share all those worries with your family. That is where nurses, psychologists and other medics can really be of support. Or support groups like the Marie Keating Foundation or any other cancer groups,” says Dr Lynch.

What the study tells us about living with cancer

Feeling misunderstood

Three quarters of the people in the study felt misunderstood.

“Although they had a loving husband or wife, they just didn’t feel understood,” said Dr Lynch.

Biggest mistakes made by those you meet

The study group felt that the biggest mistake other people made was to think that they had to do something in order to ‘fix’ the situation. Onlookers can feel helpless.

Oncologist can’t always give good news

People with advanced breast cancer just want their oncologist to say, ‘Everything is going to be okay’. But that’s not what an oncologist can always say.

Friends and family can say the wrong thing

Close family or friends can be aggravating when they say things like: 'Well you know what, you're a fighter and you'll survive it'. That puts an expectation on the person.

Some days are just st!**

"Some days people in the study group felt like fighting it and they felt strong in themselves, but other days people said: 'It was just shit and I wanted to feel shit. Allow me to feel like shit. Don't make me constantly have to fight this, because I'm tired'. This is something people with cancer say often," says Dr Lynch.

People should ask what you need

It can help when friends and family just say: 'What do you need?' People know what they need, but until they get asked, sometimes they can't say it.

Palliative care is not just for end of life

Palliative care for cancer pain

Palliative care is about control of symptoms it's not just for end of life. It is about improving the quality of life and learning to cope with the symptoms you have.

“Many people mistakenly believe that you can only receive palliative care when other treatments are no longer possible. Actually, palliative care can be provided to people of any age and at any stage of their illness,” says Dr Aisling O’Gorman, Consultant Palliative Care Specialist.

“Providing palliative care at an early stage in a person’s illness, for example, while using therapies such as chemotherapy and radiation can help to better manage symptoms and complications,” says Dr O’Gorman.

Palliative care is not just about treatment at the end of life. You will be put in contact with the palliative care team at times when your pain needs are high and complex. In palliative care the healthcare team do an ‘impeccable assessment’. This means that all your needs are considered including:

- physical;
- spiritual;
- social; and
- psychological.

Once your needs in these areas have been addressed you will step back again from the palliative care team. Palliative care is delivered periodically as you need it and it follows the needs of the individual and their family. Palliative care is delivered:

- in hospital;
- in the community;
- as a day patient in a hospice; or
- as an in-patient in a hospice.

As a day-patient in a hospice you might attend once a week for six weeks. During this time you might receive physiotherapy and other therapies. You may be seen by the medical team, the nursing staff and other members of the hospice team.

The hospices work hand-in-hand with other healthcare institutions like hospitals.

“Women are often apprehensive about coming into the hospice in the first place. But we see women going home with their symptoms controlled and being able to live their life as well as they can at home,” says Vicki McCullagh who is a Specialist Palliative Care nurse at Our Lady’s Hospice in Harolds Cross, Dublin.

How can the palliative care team help?

Common physical symptoms that the palliative care team can address are:

- pain;
- nausea;
- fatigue;
- breathlessness associated with lung metastases; and
- bowel issues.

“The treatment for the cancer can often be holding things, but not improving them. So we look at other medicines or non-medical techniques that can help to improve symptoms,” says Consultant Palliative Care Specialist, Dr Aisling O’Gorman.

“For example, it can be a medicine, but so often it is not. If somebody has a lot of back pain, it may be particular seating or a mattress that they need.

“If somebody has breathlessness or fatigue, you look at energy conservation strategies. Occupational therapists and physiotherapists have a big role in helping somebody to do what they want and need to do in a way that doesn’t drain or exhaust them.

“We will make suggestions. If you have a limited amount of energy we may ask you questions like ‘would you rather use that energy for getting washed and dressed in the morning? Or would you rather get someone to help you with that, so you can have the energy for being with your kids later on in the day?’” says Dr O’Gorman.

The palliative care team also looks at psychological and social issues. Most people have mood ups and downs, which is natural. Palliative care can help to support you and build up your resilience, so you can navigate through your cancer.

“We try to support a person to live with cancer, rather than feel like they’re dying from it,” says Dr O’Gorman.

Making pain care drugs work for you

Some people worry that if they avail of pain relief in the early days there will be nothing left to work for them later on when they are more ill. However, for cancer pain the key is to get on top of it early.

“People are terribly afraid of morphine medicines. They won’t take them because they feel ‘I won’t have anything left down the line when I really need them’. That is not a good approach for cancer pain, because cancer pain is your body’s way of telling you ‘I have a problem here’, says Dr O’Gorman.

“You don’t need to be constantly reminded that you have a problem. You know there is cancer there you don’t need to be constantly given that message. That is where pain relief comes in. Catching it early, getting on top of it early, means that you are less likely to have uncontrolled pain down the line. If you allow pain to take hold of your body it becomes chronic pain and that is much more difficult to deal with,” says Dr O’Gorman.

How are pain drugs given?

There is a wide range of pain medications that can be given in a wide variety of ways. They can be:

- tablets;
- a patch;
- suppositories; or
- continuous infusion.

“People worry when they hear about the pump or the syringe driver because they think they are only for the end. But it really isn’t.

Sometimes it is for complex pain when somebody is maybe not able to swallow because they have been sick, for example, or their bowel is not working well. It can be for a fixed period of time,” says Dr O’Gorman.

It is useful to deliver medication by pump or syringe if, for example, someone’s liver is not work well because it can bypass some of the metabolism issues. Spinal pain relief can also really help.

Along with palliative care, there are specialist anaesthetists who can help with nerve blocks for particular areas.

Radiotherapy can also be a really good treatment for pain from bone metastases. Often a short course of radiotherapy can achieve this.

Planning ahead: think ahead

The 'Think ahead' scheme can help you record and register your preferences about what you want if you are very ill or dying. This scheme was devised by the National Council of the Forum on End of Life in Ireland.

The programme gives people control and choice. It can help you be responsible for what happens in the future.

Family members may want to prolong your life at all costs. That may not be what you want. There are lots of care preferences that you can consider.

- How do you feel about your quality of life compared to the length of your life?
- If you are dying, do you want chemotherapy or radiotherapy?

If you are very ill, you are not going to recover and you have very poor quality of life and a lot of suffering, you may feel you want to say 'thus far and no further'.

If you can write down your preferences while you are still able to, it can save a huge amount of conflict, heartache and hassle.

If you take part in the 'Think ahead' project, it means you will get the type of care that you want. It can make what is a very difficult time for everyone that bit easier.

Let people know your wishes

'Think ahead' lets you answer questions like:

- Who would you like included in discussions about your medical condition or care?
- Are there cultural preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

The form lets you say what your care preferences would be if you were so ill that you could not speak for yourself. It allows you to set out your preferences about the medical treatments that you do not want to receive in the future in case you cannot speak for yourself. It also allows you to name someone, called a 'Patient-Designated Healthcare Representative', who can speak on your behalf.

You should speak to a healthcare professional before completing the form. They may be the best person to give you the information you need when deciding about the care and treatment you would like.

You can print out a 'Think ahead' form to fill in your preferences here:

<http://www.thinkahead.ie/think-ahead-form-2/>

Hospice Foundation and other palliative services

The Irish Hospice Foundation runs a Hospice Friendly Hospitals Programme to make sure that end of life, palliative and bereavement care are central to the everyday business of hospitals.

The programme aims to improve the standard of end-of-life care in hospitals. More than 40 public and private hospitals are now linked to the programme.

There are seven End-of-Life Coordinators in position in hospitals across the country.

For more information

Website: www.hospicefriendlyhospitals.ie;

Phone: 01- 679 3188; or

Email: hfh@hospicefoundation.ie

Hospice care

Hospice care aims to improve the lives of people whose illness is no longer curable. It helps them to live as fully as possible to the end. It seeks to relieve the physical symptoms of illness while equally addressing the patient's emotional and spiritual needs. Hospice care also provides support to families and those who are important to the patient, and extends its reach into bereavement.

Hospice care can be provided in various care settings, such as a hospice, people's homes, a hospital or a nursing home.

Palliative care

The terms 'hospice care' and 'palliative care' are sometimes used interchangeably. Palliative care is the term generally used by those working in the health service.

Palliative medicine is a recognised medical specialty in Ireland. A doctor specialising in this area is known as a Consultant Physician in Palliative Medicine or Palliative Care Consultant. Specially trained nurses working in hospices, or as part of a specialist palliative care team in a hospital or in the community, are Clinical Nurse Specialists (CNS) in Palliative Care. Palliative care aims to improve the quality of life of patients and their families facing the problem associated with life-threatening illness. It does this by preventing and relieving suffering by:

- identifying problems early;
- assessing and treating pain; and
- assessing and treating other problems – physical, psychosocial and spiritual.

End-of-life care

Not everyone means the same when they talk about ‘end-of-life care’. The Irish Hospice Foundation uses this term to refer to all aspects of the care provided to a person with a life-limiting illness:

- from the time of diagnosis;
- through the last months of life; and
- up to and including the final hours.

For more information about hospice care in Ireland

Website: www.hospicefoundation.ie

Phone: 01-679 3188

Email: info@hospicefoundation.ie

Legal Affairs

If you are very ill or dying you will probably want to organise your legal affairs. To do this you need to think about:

- making a will;
- making financial or other provisions for family members; and
- appointing guardians for children under 18.

You may also wish to appoint an attorney under Enduring Power of Attorney. The attorney would be able to make decisions on your behalf if you become unable to do so. You may want to give your attorney the authority to refuse life-sustaining treatment on your behalf.

Financial planning

You may want to talk to your solicitor about appointing one person to manage your financial affairs on your behalf. The 'Think ahead' form mentioned earlier allows you to fill in details about:

- bank accounts;
- insurance policies for things like your home, property and car;
- life assurance;
- credit cards;
- tax affairs;
- pensions;
- mortgage documents;
- house deeds;
- other assets; and
- any debts.

How the Marie Keating Foundation can help you

The Marie Keating Foundation's aim is "Making cancer less frightening by enlightening".

The Foundation is now a leading voice in cancer awareness and information for both men and women in Ireland.

We provide information on all the key cancers, including:

- bowel cancer;
- breast cancer;
- cervical cancer;
- lung cancer;
- prostate cancer;
- skin cancer;
- testicular cancer; and
- throat cancer.

All of our cancer awareness and support services are provided free of charge to individuals, schools and community groups all around the country.

Ask the nurse

Our 'Ask the nurse' service means you can get information about any aspect of cancer from a qualified, expert nurse. You can submit your question on line at

www.mariekeating.ie/cancer-information-services/ask-the-nurse/

Our nurse will respond to you in complete confidence to the email address that you supply.

Marie Keating Foundation Comfort Fund

We provide financial help to people who are receiving treatment for any kind of cancer and who find themselves in financial difficulty as a result. A diagnosis of cancer can lead to:

- increased medical costs such as consultant fees and expensive medications;
- additional expenses from activities such as increased travel to medical appointments that may be some distance from home;
- increased utility bills due to extra time at home while recovering from treatment; and
- reduction in earnings where a patient and perhaps their family members have to take time off work.

Many people can find themselves overwhelmed by these costs and this adds to the stress associated with their cancer diagnosis. We hope to reduce that burden.

Each year, the Marie Keating Foundation allocates a specific budget for people who are undergoing treatment for cancer, but who are financially struggling. The fund accepts applications on behalf of men, women and children. Last year alone, the Marie Keating Foundation's Comfort Fund helped more than 534 families through their cancer journey.

How does the Comfort Fund work?

The Marie Keating Foundation works in partnership with health care professionals, mainly Medical Social Workers (MSWs) and Clinical Nurse Specialists (CNSs).

Applications must be made by the healthcare professional involved directly in your care. If you do not know who this is, ask in the centre where you are receiving treatment and they will refer you.

The Marie Keating Foundation cannot accept applications directly from patients or their family members. The Comfort Fund will consider only one application per patient.

If you are a healthcare professional or a social worker and would like more details on the Comfort Fund, please email info@mariekeating.ie or call 01-628 3726.

Contact

All courses and seminars are free to attend, but places are limited, and registration is essential. If you would like to find a course that is suitable for you, please contact:

Angela Egan

The Marie Keating Foundation

Phone: 01-628 3726

Email: info@mariekeating.ie

Useful organisations, contacts and supports

See also www.mariekeating.ie

National organisations

Name	Location	Phone	Email and/or website
Citizens Information Board	43 Townsend St, Dublin 2, D02 VK65	0761 07 4000	info@ciboard.ie www.citizensinformation.ie
EuropaDonna Ireland	PO Box 6602, Dublin 8	01-496 0198	info@europadonnaireland.ie www.europadonnaireland.ie
Family Carers	Nationwide	1800 240 724	info@familycarers.ie http://familycarers.ie/
Hospice Friendly Hospitals	Nationwide	01- 679 3188	hfh@hospicefoundation.ie www.hospicefriendlyhospitals.ie
Irish Brain Tumour Support Group	St Luke's Hospital, Dublin 6	01-406 5163	www.braintumoursupport.ie
Irish Cancer Society	Head office, 43/45 Northumberland Road, Dublin 4	01-231 0500 1800 200 700	support@irishcancer.ie www.cancer.ie

Useful organisations, contacts and supports

Support groups and centres – National organisations continued			
Name	Location	Phone	Email and/or website
Irish Hospice Foundation	32 Nassau Street, Dublin 2, D02 YE06	01-679 3188	info@hospicefoundation.ie www.hospicefoundation.ie
Irish Nutrition & Dietetic Institute	Ashgrove House, Kill Avenue, Dun Laoghaire, Co Dublin	01-280 4839	info@indi.ie www.indi.ie
LARCC (Lakelands Area Retreat & Cancer Centre)	Multyfarnham, Mullingar, Co Westmeath.	044-9371971 1850 719 719	http://cancersupport.ie/ info@cancersupport.ie
Lymphoedema Ireland	C/O The Irish Cancer Society, 43/45 Northumberland Road, Dublin 4	Freefone 1800 200 700 087-693 4964	info@lymphireland.com http://lymphireland.com/
Marie Keating Foundation	Unit 9 Millbank Business Park, Lucan, Co Dublin	01-628 3726	info@mariekeating.ie www.mariekeating.ie
Medical card application		Call Save 1890 252 919	clientregistration@hse.ie www.hse.ie/eng/cards-schemes/medical-card/

Support groups and centres – National organisations continued			
Name	Location	Phone	Email and/or website
Money Advice and Budgeting Service (MABS)	Nationwide	0761 07 2000	helpline@mabs.ie www.mabs.ie
Plurabelle Paddlers	Grand Canal Dock Dublin – Rowing club for people with breast cancer	087-280 6048	info@plurabellepaddlers.com www.plurabellepaddlers.com
St Luke’s Breast Cancer Support Group	St Luke’s Hospital, Dublin 6	01-406 5163	http://stlukesnetwork.ie/patients/patient-support/support-groups-and-programmes.html
Think Ahead Planning For death and dying	32 Nassau Street, Dublin 2	01-679 3188	info@hospicefoundation.ie http://hospicefoundation.ie/
Health insurers			
AVIVA Health (formerly VIVAS Health)	1 Park Place, Hatch Street, Dublin 2.	1850 45 35 25	www.aviva.ie/health
Laya Healthcare (formerly Quinn)	Eastgate Road, Eastgate Business Park, Little Island, Co. Cork	021-202 2000	www.layahealthcare.ie

Useful organisations, contacts and supports

Regional support groups and centres			
Name	Location	Phone	Email and/or website
LEINSTER			
ARC Cancer Support Centre	Arc House, 65 Eccles Street, Dublin 7	01-830 7333	info@arccancersupport.ie http://arccancersupport.ie/
ARC Cancer Support Centre	557-559 South Circular Road, Dublin 8	01-707 8880	info@arccancersupport.ie www.arccancersupport.ie
Arklow Cancer Support Centre	8 St. Mary's Road, Arklow, Co Wicklow	040-235 90	arklowcancersupport@gmail.com http://arklowcancersupport.ie/
Athlone Breast Cancer Support Group	C/O Cancer Support Sanctuary, LARCC, Coole Road, Multyfarnham, Co Westmeath	1850 719 719 044-937 1971	info@cancersupport.ie http://cancersupport.ie/
Balbriggan Cancer Support Group	Unit 23, Balbriggan Business Park, Co Dublin	01-841 0116 087-353 2872	www.balbriggan.info/ balbriggan-cancer-support-group/
Brain Tumour Ireland	8 Kilgobbin Lawn, Stepside, Co Dublin		info@braintumourireland.com https://braintumourireland.com/

Support groups and centres – Leinster continued

Name	Location	Phone	Email and/or website
Canteen Ireland – support for young people with cancer	4 Carmichael Centre, North Brunswick Street, Dublin 7	01-872 2012	info@canteen.ie www.canteen.ie
Cara Cancer Support Centre	7 Williamson Place, Dundalk, Co Louth	042-933 9383 087-395 5335	info@ccscdundalk.ie www.ccscdundalk.ie
Cois Nore Kilkenny Cancer Support Centre	8 Walkin Street, Kilkenny, Co Kilkenny	056-775 2222	https://coisnore.ie/
Cuisle Centre	Block Road Portlaoise Co Laois	057-868 1492	info@cuislecancersupport-centre.ie www.cuislecentre.com
Dochas Offaly Cancer Support	Teach Dóchas, Offaly Street, Tullamore, Co Offaly	057-932 8268	info@dochasoffaly.ie www.dochasoffaly.com
Éist Cancer Support Centre Carlow	The Waterfront, Mill Lane, Carlow	059-913 9684 085-144 0510	info@eistcarlowcancersupport.ie www.eistcarlowcancersupport.ie

Useful organisations, contacts and supports

Support groups and centres – Leinster continued

Name	Location	Phone	Email and/or website
Gary Kelly Cancer Support Centre	George's Street, Drogheda, Co Louth	041-980 5100	info@gkcancersupport.com www.gkcancersupport.com
Greystones Cancer Support	La Touche Place, Greystones, Co Wicklow	01-287 1601	info@GreystonesCancerSupport.com
Haven Cancer Support and Therapy Group	Haven House, 68 Hazelwood, Gorey, Co Wexford	053-942 0707	info@thehavengroup.ie www.thehavengroup.ie
Hope Cancer Support Centre	22 Upper Weafer Street, Enniscorthy, Co Wexford	053-923 8555	info@hopesupportcentre.ie www.hopesupportcentre.ie
Lakelands Area Retreat & Cancer Centre	Ballinalack, Mullingar, Co Westmeath	044-937 1971; Callsave 1850 719 719	info@larcc.ie www.larcc.ie
Rathdrum Cancer Support Centre	St Anne's, Rathdrum, Wicklow.	087-691 7675	rathcan@gmail.com

Support groups and centres – Leinster continued			
Name	Location	Phone	Email and/or website
Tallaght Cancer Support Group	1-2 Main Street, Tallaght, Dublin 24	086-400 2736 086-400 2703	ctallaght@yahoo.ie http://tallaghtcancer-support.com/
Wicklow Cancer Support Centre	Unit 2, Rear of Butlers Medical Hall Pharmacy, Abbey Street, Wicklow	0404-32696	wicklowcancersupport@gmail.com
CONNAUGHT			
Athenry Cancer Care	Social Service Centre, New Line, Athenry, Co. Galway	091-844 319 087-412 8080	athenrycancercare@gmail.com http://athenrycancer-care.ie/
Ballinasloe Cancer Support Centre	Society Street, Ballinasloe, Co Galway	090-964 5574 087-945 2300	http://ballinasloecancer-support.ie/
Cancer Care West	Inis Aoibhinn, University Hospital Galway, Costello Road, Galway	091-545 000	info@cancercarewest.ie www.cancercarewest.ie

Useful organisations, contacts and supports

Support groups and centres – Connaught continued			
Name	Location	Phone	Email and/or website
Cara Iorrais Cancer Support Centre	2 Church Street, Belmullet, Co Mayo	097-20590	caraiorrais@gmail.com www.caraiorrais.com
Galway East and Midlands Cancer Support Centre	Le Chéile, Brackernagh, Ballinasloe, Co Galway	090-964 2088	info@egmcancersupport.com www.egmcancersupport.com
Gort Cancer Support Group	Garrabeg, Gort Co Galway	091-648 606 086-172 4500	info@gortcancersupport.ie www.gortcancersupport.ie
Hand in Hand Children's cancer society	Main Street, Oranmore, Co Galway	091-483 694	info@handinhand.ie www.handinhand.ie/
Mayo Cancer Support Association	Rock Rose House, 32 St Patricks Avenue, Castlebar, Co Mayo	094-903 8407	info@mayocancer.ie www.mayocancer.ie
Roscommon Cancer Support Group	Vita House Family Centre, Abbey Street, Roscommon	090-662 5898	lauramullooly@vitahouse.org https://roscommoncancer-support.ie/

Support groups and centres – Connaught continued

Name	Location	Phone	Email and/or website
Sligo Cancer Support Centre	44 Wine Street, Sligo, Co Sligo	071-917 0399	scsc@eircom.net
Tuam Cancer Care Centre	Cricket Court Dunmore Road Tuam, Co Galway	093-285 22	support@tuamcancercare.ie www.tuamcancercare.ie
MUNSTER			
CARE Cancer Support Centre	14 Wellington Street, Clonmel, Co Tipperary	052-618 2667	caresupport@eircom.net https://cancercare.ie/
Circle of Friends Cancer Support Centre	4, 6 & 7 Station House, Station Road, Tipperary Town	087-3412600	circleoffriendstipp@gmail.com www.circleoffriendscancersupport.com/
Clare Cancer Support Sláinte on Chláir:	Kilnamona, Ennis, Co Clare	1850 211 630 087-691 2396	admin@clarecancersupport.com www.clarecancersupport.com
Cork ARC Cancer Support House	Cliffdale, 5 O'Donovan Rossa Road, Cork	021-427 6688	info@corkcancersupport.ie www.corkcancersupport.ie

Useful organisations, contacts and supports

Support groups and centres – Munster continued			
Name	Location	Phone	Email and/or website
Cork Brain Tumour Support Group	Chemotherapy Department of Cork University Hospital, Wilton, Cork	087-146 5742	
Cunamh Bons Secours Cancer Support Group	Bon Secours Hospital, College Road, Cork	021-480 1676	
Kerry Cancer Support Group	124 Tralee Town House Apartments, Main Street, Tralee, Co Kerry	066-719 5560	kerrycancersupport@eircom.net www.kerrycancersupport.com
Midwestern Cancer Support Centre	University Hospital Limerick, Dooradoyle, Limerick	061-482 900	www.midwesterncancercentre.ie
Recovery Haven	5 Haig's Terrace, Tralee, Co Kerry	066-719 2122	reception@recoveryhavenkerry.com www.recoveryhavenkerry.com
South Eastern Cancer Foundation The Solas Centre	Solas Cancer Support Centre, Williamstown, Waterford.	051-304 604	info@solascentre.ie https://solascentre.ie/

Support groups and centres – Munster continued			
Name	Location	Phone	Email and/or website
Suimhneas Cancer Support Centre	2 Clonaslee, Gortland Roe, Nenagh, Co Tipperary	067-37403	suaimhneascancersup- port@eircom.net
Suir Haven Cancer Support Centre	Clongour Road, Clongour, Thurles, Co Tipperary	0504-211 97	suirhaven@gmail.com
West Cork Cancer Support	'The Bungalow' at Bayview Gories, Goureebeg, Bantry, Co. Cork	027-53 891 083-198 8580	westcork@corkcancer- support.ie /www.corkcancersupport. ie/west-cork-services-1/
Youghal Cancer Support Group (Opened in 2017)	29 Friar St, Youghal-Lands, Youghal, Co Cork	024-91654	

Ireland's eight Designated Cancer Centres

Hospital Group	Cancer Centre	Phone	HSE Region
RCSI	Beaumont University Hospital www.beaumont.ie/oncology	Main switch: 01-809 3000	HSE Dublin – North East
Ireland East	Mater University Hospital www.mater.ie	Main switch: 01-803 2000	HSE Dublin – North East
	St Vincent's University Hospital www.stvincents.ie	Main switch: 01-221 4000	HSE Dublin – Mid Leinster
Dublin Midlands	St James's University Hospital www.stjames.ie	Main switch: 01-410 3000	HSE Dublin – Mid Leinster
South/Southwest	Cork University Hospital www.cuh.hse.ie	Main switch: 021-492 2000	HSE South
	Waterford Regional Hospital www.hse.ie/eng/services/list/3/acutehospitals/hospitals/waterford/	Main switch: 051-848 000	HSE South
Saolta University	Galway University Hospital www.saolta.ie/hospital/university-hospital-galway	Main switch: 091-524 222	HSE West
	Satellite: Letterkenny General Hospital www.hse.ie/go/LGH/	Main switch: 074-912 5888	
Midwest	University Hospital Limerick www.hse.ie/eng/services/list/3/acutehospitals/hospitals/ulh/hospitals/uhl/	Main switch: 061-301 111	HSE West

Index

What is advanced breast cancer?	4
Main types of advanced breast cancer	4
Symptoms of advanced breast cancer	5
Where cancer can spread	6
Symptoms if cancer has spread to the lymph nodes.....	6
Symptoms if cancer has spread to the bones	7
Symptoms if cancer has spread to the bones	7
Symptoms if cancer has spread to the liver	8
Symptoms if cancer has spread to the lungs.....	8
Symptoms if cancer has spread to the brain	9
What does ‘secondary’ mean?.....	9
What does ‘metastases’ mean?	9
If it has spread to your bones it is still breast cancer	9
‘De novo’ breast cancer	10
Recurrent advanced breast cancer	10
Why did I get advanced breast cancer?	10
Why was it not found earlier?	11
How long will I live?	12
Keeping a diary can be helpful.....	13
What should a woman watch out for during treatment?.....	14
What questions should a woman ask	14
Questions for your first appointment.....	15
Questions for your second appointment.....	15
Difficult questions	15
Can I get a second opinion?	16
Future therapies.....	16
Coping with your diagnosis.....	17
Coping practically with advanced breast cancer	18

Ask for help	18
Staff can support you	18
What to expect	19
What type of treatment will I need?.....	19
Managing cancer fatigue	20
Learning to manage fatigue.....	21
About cancer pain	24
Specialist surgeons	26
Specialist medical oncologist	26
Oncology liaison nurses	27
Public Health and Community Nurses	27
Radiation oncologist.....	28
Clinical Nurse Specialists (CNS).....	28
Psycho-oncologists.....	28
Where to go for complementary therapy.....	29
Palliative care specialists.....	31
Counselling organisations	31
Your emotions and cancer.....	33
There's no right or wrong.....	33
How you may feel when you are diagnosed	33
Shock	33
Denial.....	34
Other people being in denial	35
If you are a friend or relative	35
Highs and lows of living with advanced breast cancer	36
Your emotions during treatment	38
Understanding your feelings	38
Asking for help.....	39
Support outside the family	39

Evelyn Wakefield tells us about living with advanced breast

cancer40

Fatigue.....	41
Conserve your energy	42
Keep home life simple	42
Adapt your house to your needs	43
Dealing with chemotherapy.....	43
Keep a diary of symptoms, medication and treatment	44
Talking to friends and family.....	45
When telling her family Evelyn was very candid.....	45
Make a will.....	46

Diet and nutrition.....47

General diet tips	48
Food hygiene.....	50

Exercise and advanced breast cancer53

How you can help prevent lymphoedema.....	53
---	----

Avoiding and managing lymphoedema54

What can I do to prevent lymphoedema?	55
Cancer and sexuality	59

Coping with the financial

implications of cancer.....62

Benefits for people who are sick or have a disability	62
Medical card application form.....	64
Mortgages, loans, pensions and insurance.....	65
Health insurance.....	66
Prostheses, bras and appliances	66
Financial implications: useful contacts.....	67

Making the most of every day	68
Marie Keating Foundation Positive Living programme	68
Europa Donna Ireland.....	69
Plurabelle Paddlers.....	70
Coping psychologically with terminal illness.....	72
Show yourself compassion	73
What the study tells us about living with cancer	75
Palliative care is not just for end of life	77
Palliative care for cancer pain	77
How can the palliative care team help?	79
Planning ahead: think ahead	82
Let people know your wishes.....	83
Hospice Foundation and other palliative services.....	83
Hospice care	84
Palliative care	84
End-of-life care.....	85
Legal Affairs.....	86
Financial planning.....	86
Ask the nurse.....	87
Marie Keating Foundation Comfort Fund	88
Survive & Thrive.....	90
Contact.....	91
Useful organisations, contacts and supports.....	92

About the Marie Keating Foundation

Following their mother Marie's death in 1998, the Keating family promised that they would do everything they could to bring an end to cancer. They committed to provide all Irish people with the necessary information to prevent cancer or detect it at its earliest stages. Their collective aim was "Making cancer less frightening by enlightening".

Through its community information service, the Foundation's dedicated nurses have enlightened more than 225,000 people about the causes and risk factors of cancers. The Foundation is continuing to expand its awareness campaigns on the most common cancers affecting men and women in Ireland. It is doing this at local level through its community outreach approach as well as through national campaigns.

Through its Comfort Fund, the Foundation provides financial assistance to people who are currently receiving treatment for any kind of cancer and who, as a result, find themselves in financial difficulty. In 2015 alone, more than 350 families received assistance from the Comfort Fund.

On 2 February 1998, our mother, Marie died from breast cancer. Throughout her illness, we could do nothing to help the amazing person who had done everything for us, all our lives. We, the Keating family, have set up this charity in her name to try to prevent others going through what our family went through. This is also to ensure that such a wonderful person did not die in vain.

Take care,



Marie Keating
FOUNDATION

This booklet was produced
with the kind support of



NOVARTIS
ONCOLOGY