

Coping with advanced melanoma



Marie Keating
FOUNDATION

making cancer less frightening by enlightening

About this booklet

This booklet is about coping with advanced melanoma. Also known as Stage 4, advanced melanoma means the melanoma has spread from where it started to another part of the body.

Coping with advanced melanoma can be difficult. This booklet will help you and your family to understand your disease and its management, who your care givers are and how they can support you. The booklet looks at the symptoms you might experience, the strong emotions you may feel and the difficulties you may encounter. It also hopes to highlight practical details that you may have to consider in your future and advice on how to access additional supports and services.

Parts of this booklet, particularly towards the end, may be difficult or upsetting to read as they deal with issues about the end of life. If you do read on, consider having someone close by to support you.

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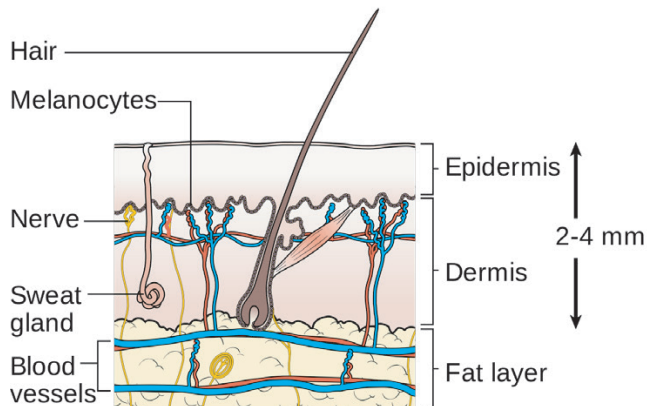
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What is melanoma?

Your skin is the largest organ in the body. It regulates body temperature and keeps moisture within the body while protecting your other organs and shielding them from harmful external agents called pathogens.

The skin is composed of three layers: the outermost epidermis, the supporting dermis and the hypodermis or fat layer. Melanocytes, the cells which produce the melanin which are responsible for our skin colour, are found in the epidermis.

The skin:



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Skin cancer arises when the DNA of the skin cells in the epidermis are damaged, resulting in uncontrolled growth of these injured cells. Ultraviolet (UV) radiation, from the sun or from sun beds, is the cause of this damage in 90% of cases.

Over 980 people are diagnosed with melanoma in Ireland each year and this number rises annually. Though melanoma is the least common type of skin cancer, it is the most serious. If diagnosed early, it is almost always curable. However, if left untreated, it can spread, or metastasize, to other parts of the body, causing serious and sometimes fatal illness.

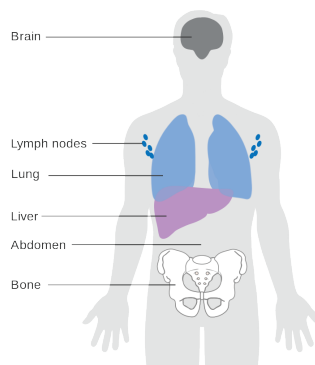
How does melanoma start?

Melanoma may evolve over weeks, months or even years. Initially, it may take the shape of a new mole, or freckle-like spot on the skin, or it might develop in an existing mole. Melanomas are usually dark-coloured (brown or black); however, some tumours show a mixture of colours, including blue, grey and red.

Melanoma can affect any part of the body, including areas not usually exposed to the sun, such as the genital or anal area. Other parts of the body such as the mouth, eyes, or nail beds may also be affected.

Men are most commonly affected by melanoma on the back or the chest while women are most commonly affected on the back and legs. Melanoma grows through the skin to the fat below, and has a tendency to spread through lymph and blood. (Lymph is a clear fluid that travels through your body's arteries, circulates through your tissues to cleanse them and keep them firm, and then drains away through the lymphatic system.) Melanoma of the skin most commonly spreads to the lymph nodes, lungs, brain, spinal cord and liver, although it can potentially spread anywhere in the body.

Common places for melanoma to spread:

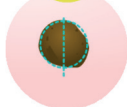


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Spotting melanoma

It is vital that each of us gets to know our skin and checks it regularly- at least once a month. If you have been diagnosed with melanoma, this is particularly important as you are at increased risk of a reoccurrence. You should examine your entire body from top to toe for changes, including parts that we often forget about like the backs of the knees, the bottom of the feet and the back. It may help to use a mirror or ask a partner or close family member to help. You can use the ABCDE method to help you assess if any of your freckles or moles are changing or should be looked at by your doctor:

A



Asymmetry

If you draw a line through a melanoma, the two sides will not match

B



Border

The border of an early melanoma tends to be uneven. The edges may be scalloped or notched

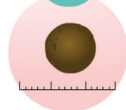
C



Colour

Most healthy moles are all one colour. A mole with a number of different shades of brown, black or tan is a warning sign. Melanomas may also be blue, red or some other colour

D



Diameter

Melanomas are usually larger in size than the rubber at the top of a pencil ($\frac{1}{4}$ inch or 6mm)

E



Evolving

Any change in shape, colour, size, elevation (height), or any other trait, or a new symptom like bleeding, itching or crusting is a warning sign.

Protecting your skin- the SunSmart code

When you have been diagnosed with melanoma, it is vital that you are even more careful about protecting your skin. You can do this following the SunSmart code.

Always wear sunscreen with a high SPF factor

Apply the sunscreen 20-30 minutes before going outside, even if it is not sunny. Remember that if you are out in the sun, you should apply thickly and evenly every two hours no matter how high the Sun Protection Factor (SPF) protection. Apply the equivalent of a shot glass full of sunscreen to each limb and to your body and about half this much to your face. Always reapply after swimming or perspiring. Remember no sunscreen gives 100% protection from the sun. You should wear at least SPF 30. The higher the SPF the better.

Use sunscreen with UVA and UVB protection

Choose a sunscreen that has good protection against UVA and UVB rays. This is because both UVA and UVB rays can cause skin cancer. In Ireland, the level of UVA protection might be shown in one of two ways

- Star rating
- A symbol with the letters UVA inside a circle

The SPF measures a sunscreen's ability to filter UVB rays so the higher the SPF, the more protection you have against UVB.

Avoid the sun between 11am and 3pm

This is when the sun's rays are strongest. This applies all year round, not just in summer. It is important to remember that the sun's rays are present even on a cloudy day.

Wear protective clothing

Clothing should be dark and tightly woven and cover your arms and legs. Wear a broad-brimmed hat that provides lots of shade. Remember to protect your eyes too by wearing sunglasses. Choose a wraparound pair that gives UV protection. Check the sunglass tags to ensure that they give good protection. You can look out for these quality marks:

- European Standard EN1836
- British Standard BS 27241987

Check the UV Index

If the UV Index is more than 3, you need to be more SunSmart.

Never, ever use sunbeds

Sunbeds are not a safe alternative to tanning outdoors. The intensity of some of the UV rays they give off can be 10 to 15 times higher than that of the midday sun. Using a sunbed, even just once, increases the risk of melanoma by 20%. Using a sunbed before the age of 35 increases your risk by almost 60%.

Symptoms of melanoma

The symptoms depend on where the cancer is in the body. They might include:

- hard or swollen lymph nodes
- a hard lump on your skin
- unexplained pain
- feeling very tired or unwell
- unexplained weight loss
- yellowing of eyes and skin (jaundice)
- build-up of fluid in your tummy (abdomen) - ascites

If it has spread to your lymph nodes:

- Lymph nodes may feel or swollen.
- Swollen lymph nodes in the neck area can make it hard to swallow.
- Cancer cells can also stop lymph fluid from draining away, possibly leading to swelling in the neck or face due to fluid build-up in that area. This swelling is called lymphoedema.

If the cancer has spread to your lungs, you may experience:

- a cough that doesn't go away
- breathlessness
- ongoing chest infections
- coughing up blood

You might have any of the following symptoms if your cancer has spread to the liver:

- discomfort or pain on the right side of your tummy (abdomen)
- a swollen tummy (called ascites)
- feeling sick
- poor appetite and weight loss
- yellowing of the skin and whites of the eyes (jaundice)
- itchy skin

Cancer that has spread to the bones may cause the below symptoms:

- pain – this pain is continuous and people often describe it as gnawing
- backache, which gets worse despite resting
- weaker bones – they can break more easily
- raised blood calcium (hypercalcaemia), which can cause dehydration, confusion, sickness, tummy (abdominal) pain and constipation
- low levels of blood cells – blood cells are made in the bone marrow and can be crowded out by the cancer cells, causing anaemia, increased risk of infection, bruising and bleeding

You might have any of the following symptoms if your cancer has spread to your brain:

- headaches
- feeling sick
- weakness of a part of the body
- fits (seizures)
- personality changes or mood changes
- eyesight changes
- confusion

You may experience the following symptoms if your melanoma is found in your eye, which is a rare condition known as ocular melanoma:

- blurred vision
- seeing flashing lights and shadows
- brown or dark patches on the white area of the eye

These symptoms can be caused by other eye conditions but if you experience them, it is a good idea to get them checked.

Stages of melanoma

The 'stage' of a cancer means how big it is and whether or not it has spread. This is important because treatment is often based on the stage of a cancer.

Diagnosing the stage of cancer

'Clinical' stage testing

The examination, tests and scans you have when diagnosing your cancer gives information about the 'clinical' stage.

'Pathologic' stage testing

During surgery the doctor finds out more about the cancer. The tissue the surgeon removes, including the lymph nodes, is carefully examined in the laboratory. These results are combined with the clinical stage to give a 'pathological' stage. This is more accurate than the clinical stage.

The pathological stage may be different to the clinical stage. For example, the surgeon may find that the cancer is more advanced than it looked on the scans.

On your staging report, you may see a lower case letter (c or p) written before the stage. This shows that it is the clinical or pathological stage.

TNM staging system

Your doctor will then decide what 'stage' your cancer is at using the 'TNM' staging system. TNM stands for:

- Tumour
- Node
- Metastasis.

The TNM staging system describes:

- The size of a primary tumour (T);
- If any lymph nodes contain cancer cells (N); and
- If the cancer has spread to another part of the body (there is metastasis) – (M).

T – Tumour

Tumour describes the thickness of the melanoma.

There are 5 main stages of tumour thickness in melanoma – Tis to T4.

Tis (in situ) means the melanoma cells are only in the very top layer of the skin surface

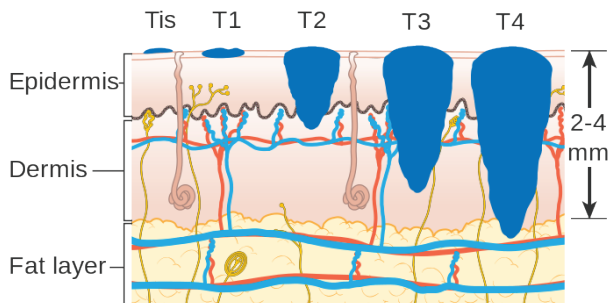
T1 means the melanoma is less than 1mm thick

T2 means the melanoma is between 1mm and 2mm thick

T3 means the melanoma is between 2mm and 4mm thick

T4 means the melanoma is more than 4mm thick

The T stages of melanoma:



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The T part is further divided into 2 groups, a and b, depending on ulceration. This describes whether or not the skin covering the tumour is broken.

Ta means the melanoma is not ulcerated

Tb means the melanoma is ulcerated

Thin melanomas (T1) are also staged depending on the mitotic rate. Mitotic rate means the number of cells that are in the process of dividing in a certain amount of melanoma tissue. A higher mitotic rate means that there are more cells dividing at a higher rate.

T1a melanomas are not ulcerated and have a mitotic rate of less than 1/mm (squared)

T1b melanomas have a mitotic rate of 1/mm (squared) or more

Ulcerated melanomas and those with a higher mitotic rate have a greater risk of spreading.

Node (N)

There are 4 stages describing whether cancer cells are in the nearby lymph nodes or lymphatic ducts – N0 to N3.

N0 means that the nearby lymph nodes do not contain melanoma cells

N1 means there are melanoma cells in one lymph node

N2 means there are melanoma cells in 2 or 3 lymph nodes

N3 means there are melanoma cells in 4 or more lymph nodes

Na, Nb and Nc

The N part of the stage is further divided into groups a, b and c.

Na means the cancer in the lymph node can only be seen by microscope (micrometastasis)

Nb means there are obvious signs of cancer in the lymph node (macrometastasis)

Nc means that there are melanoma cells in small areas of skin very close to the primary melanoma (satellite metastases) or in the skin lymph channels (in transit metastases)

Metastasis (M)

Metastasis (M) describes whether the cancer has spread to a different part of the body.

There are 2 stages of metastasis – M0 and M1:

M0 means the cancer has not spread to another part of the body.

M1 means the cancer has spread to another part of the body.

M1 is split into M1a, M1b and M1c.

- M1a means there are melanoma cells in the skin and in other parts of the body or in lymph nodes far away from where the melanoma started growing
- M1b means there are melanoma cells in the lung
- M1c means there are melanoma cells in other organs, or the melanoma causes a high level of a chemical made by the liver (lactate dehydrogenase)

Melanoma in situ (stage 0)

Melanoma in situ is also called stage 0 melanoma. It means there are cancer cells in the top layer of skin (the epidermis). The melanoma cells are all contained in the area in which they started to develop and have not grown into deeper layers of the skin.

Stage 1

Stage 1 is part of the number staging system and means the melanoma is at an early stage. It is only in the skin and there is no sign that it has spread to lymph nodes or other parts of the body. In Stage 1, the melanoma is less than 1mm thick. A diagnosis of stage 1 melanoma means it has been caught early.

Stage 2

This means that melanoma is only in the skin and there is no sign that it has spread to lymph nodes or other parts of the body. The melanoma is between 2mm and 4mm thick in this stage, except in Stage 2C where the melanoma is thicker than 4mm.

Stage 3

Stage 3 means that cancer cells have spread deeper into skin, lymph vessels, or lymph glands close to the melanoma. It depends on a number of factors including ulceration. Ulceration is when the skin covering the melanoma is broken.

Stage 3 can be divided into 3A, 3B and 3C.

Stage 3A

Stage 3A means all the following:

- up to 3 nearby lymph nodes contain melanoma cells
- these nodes are not enlarged and the cells can only be seen under a microscope
- your melanoma is not ulcerated and has not spread to other areas of the body

Stage 3B

Stage 3B means one of the following:

- your melanoma is ulcerated and has spread to between 1 and 3 nearby lymph nodes but the nodes are not enlarged and the cells can only be seen under a microscope
- your melanoma is not ulcerated and it has spread to between 1 and 3 nearby lymph nodes and the lymph nodes are enlarged
- your melanoma is not ulcerated, has spread to small areas of skin or lymphatic channels, but nearby lymph nodes do not contain melanoma cells

Stage 3C

Stage 3C means one of the following:

- your lymph nodes contain melanoma cells, and there are melanoma cells in the skin or lymph channels close to the main melanoma

- your melanoma is ulcerated and has spread to between 1 and 3 lymph nodes nearby which are enlarged
- your melanoma may or may not be ulcerated and has spread to 4 or more nearby lymph nodes
- your melanoma may or may not be ulcerated and has spread to lymph nodes that have joined together

Stage 4

Stage 4 means that your melanoma is advanced.

The melanoma has spread elsewhere in the body, away from where it started (the primary site) and the nearby lymph nodes.

The most common places for melanoma to spread include the:

- lungs
- liver
- bones
- brain
- tummy (abdomen)
- distant lymph nodes

What is advanced melanoma?

When melanoma cannot be fully removed by surgery (Stage 3) or has metastasized (Stage 4), it is known as advanced melanoma. This is the most serious form of skin cancer. While overall metastatic survival rates have more than tripled since the 1970s, advanced melanoma is still one of the most difficult cancers to treat.

Scientists have discovered that about half of all melanomas have changes (mutations) in a specific gene called the BRAF gene. Melanoma cells with these changes make an altered BRAF protein that helps them grow. Some drugs target this and related proteins.

Before the introduction of these targeted anticancer drugs, traditional chemotherapy was used to treat patients with advanced melanoma, with limited success. Recently, targeted therapies have resulted in considerable improvement in the outcome for certain patients with advanced and metastatic melanoma. These drugs target specific genetic mutations such as BRAF and destroy cancer cells.

Another option for advanced cases is immunotherapy. This works by stimulating the patient's own immune system to attack and destroy cancer cells. There is more information on treatment options in the next chapter.

Genetic mutations

Different genetic mutations have been identified and investigated over the past decade. Identifying these molecular targets of melanoma cells has radically changed how the disease is now treated and has meant that there are significantly better outcomes for advanced cases.

A patient with advanced melanoma can have more than one genetic mutation. Melanoma is one of the cancers with the highest frequency of mutations. There are several melanoma mutations that can be tested for. Identifying the type is an important step in determining how to fight the disease.

As above, the BRAF mutation is found in nearly half of all advanced melanoma and is the most common type of genetic mutation associated with the disease. There are several forms of BRAF mutations including V600E, V600K, V600G AND V600R.

Changes to the BRAF gene can stimulate growth of the melanoma cells. The BRAF mutation is the most common type of mutation in advanced melanoma. BRAF mutation is most common in patients where tumours are not caused by chronic sun-induced damage.

If you have advanced melanoma, talk to your medical team about genetic testing. You might not need any extra tests. The doctor can sometimes do genetic tests on your melanoma cells that were removed during surgery. But sometimes the doctor needs to take another sample of your melanoma. They will tell you more about this, and about what the test will involve.

How does advanced melanoma affect you?

Coping with your diagnosis

It can be very difficult coping with a diagnosis of advanced melanoma cancer, both practically and emotionally. At first, you are likely to feel very upset, frightened and confused. You may feel that things are out of your control.

Many people wonder, “Why me?” or feel afraid. Physical and chemical changes from the treatment or the cancer itself can also affect your emotions. It is important to admit to yourself how you feel and know that it is OK to feel the way that you do.

It is also 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 better able to make decisions and cope with what happens.

Treatment for advanced melanoma can be hard. You may have side effects that generally improve over the weeks and months after treatment, but for some these may be long lasting.

Telling other people about your advanced melanoma

Only you can decide when to tell your friends and family that you have advanced cancer. Your loved ones will likely be as shocked and overwhelmed as you are when they hear the news.

Loved ones may ask what they can do to support you so think about what might help - could they bring you to hospital appointments, make some meals, help with housework, or simply provide a distraction or a listening ear? It may be that you don't need help right now but that you might in the future. If that's the case, try telling them that you appreciate their offer and you will be back in touch when you need it.

Sometimes, telling those closest to you can help you process what is happening. By talking through your situation, you may begin to solve problems and think about some issues. It may help if you write down some questions that come up during these conversations so you can remember to bring them up with your doctor or medical team.

Getting tired

It can be tiring giving people details of your illness over and over again. You can give them details of our website where they can find information about advanced melanoma and a copy of this booklet if you find that easier- www.mariekeating.ie. If you don't feel comfortable answering your family's questions, you could give your doctor permission to talk to them and explain what is going on.

Trigger points

Think about your "trigger points" or topics that are too sensitive for you to talk about. Maybe you find it difficult when people suggest you try another type of treatment? Maybe you find it difficult when people tell you not to worry or trust in God? Think about the things that people have said or could say that bother you. Then, plan a response that cuts off the conversation. For example, try something like "I really get tired of talking about cancer. Let's talk about something else." You will find the best way for you to communicate that you want to end the conversation quickly but politely.

Nominate a spokesperson

If telling lots of people about your cancer is overwhelming, consider nominating a spokesperson who can tell your wider family and friends about your condition and keep them up to date on anything you wish them to know.

Lack of understanding

Some people with advanced melanoma find telling people about their cancer difficult because there is a sense that skin cancer is "not serious." While there is a growing understanding that skin cancer, and especially melanoma, can be extremely dangerous, you may still meet people who do not know the severity of the disease. You can decide how you would like to handle this.

Perhaps try saying, "I have Stage 4 melanoma which is the most serious type of skin cancer. Unfortunately the doctors are not able to cure it, but at the moment I am able to live relatively well with the disease."

Coping practically with advanced melanoma

As well as coping with the fear and anxiety that a diagnosis of 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, such as:

- Benefits;
- Sick pay; and
- Grants.

See the later section in this booklet 'Coping with financial implications' on page 51.

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, such as a counsellor or dietitian. 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.

How cancer can affect you physically

Advanced melanoma and its treatment may cause physical changes in your body. These changes can be very difficult to cope with and may affect the way you feel about yourself.

Surgery may cause scarring. Some people may have a skin graft or a scar on a very visible part of the body. Such body changes can affect your self-esteem and the way you relate to other people, especially close family and friends. If you are having difficulty coping, you can get support to help you learn how to deal with it.

Remember that scars usually improve in appearance over time. Practically speaking, camouflage makeup can help cover up skin grafts and scars. You can also use different clothing to help you cover up or draw attention away from changes.

It may also help to try to develop a positive body image. After treatment, give yourself time to recover and adjust to any changes. Try to do things that make you feel good about yourself. This could be having a relaxing bath or spending time somewhere peaceful.

Other ideas to help improve your confidence include:

- being kind to yourself and spending time with people who support you
- writing down things you like about yourself and your appearance
- seeing yourself as a whole person and not focusing on parts of your body you don't like
- replacing negative thoughts about your body with positive thoughts
- making the most of yourself with make-up, clothes or a good hairstyle.

It may also help to talk to other people who have been through the same thing. There is a facebook group, Melanoma Awareness Ireland, which is made up of people either with or directly affected by melanoma which you may like to join. There is also the Melanoma Support Ireland group which advocates for patients and families affected by melanoma. Alternatively, it may help to find a sympathetic counsellor who can help you explore your feelings in more depth.

Another problem you may have to cope with is feeling very tired and lacking in energy a lot of the time, especially for a while after treatment or if your cancer is advanced. The 'Coping with Symptoms and Side Effects' section on page 45 of this booklet has more information.

Eight cancer centres

There are eight designated cancer centres in Ireland that provide surgery and multidisciplinary care for cancers. These centres should give you quick access to high quality diagnosis and treatment. In general, you will be referred for care to the designated cancer centre closest to your home. There is a list of these centres and contact details in the section: 'Supportive personnel'.

Some of your cancer care will be provided in a wider number of acute hospitals, for example:

- X-rays;
- CT scans;
- Blood tests;
- Chemotherapy;
- Biological therapy and;
- Palliative care

Current treatment options

Different cancers may respond to different types of treatment and your treatment plan will be designed specifically for you. Your case will be discussed at a multidisciplinary team (MDT) meeting where all specialists in melanoma come together.

Surgery

Advanced melanoma may be treated through biological therapy or chemotherapy. Because your cancer is advanced, it usually means that surgery is no longer a treatment option, though you may have had surgery to help reduce the cancer in size or in the initial stages of diagnosis and testing. In some cases, if your melanoma has spread to only a limited degree, the MDT may decide that a type of surgery called limited surgical resection may help to reduce your difficult symptoms and improve your quality of life.

When surgery is considered, careful patient selection is important and treatment must be individualized.

Factors to be considered include the severity of symptoms, pace of disease progression, previous treatment and treatment response, patient age and medical condition, and the desires of the patient. Quality of life should be the principal goal of treatment for many patients.

Biological therapies

Biological therapies are drugs that change the way that cells work and help the body control the growth of cancer.

Some seek out and destroy cancer cells. Others help the body to attack the cancer.

You can have biological therapies as:

- a drip in your arm
- an injection under the skin
- a tablet

Types of biological therapy for melanoma

The two main types of biological therapy for melanoma are:

- targeted treatments, which target gene changes
- immunotherapy drugs, which help the body's natural defence system (immune system) to find and destroy melanoma cells

If you have Stage 4 melanoma, the doctor usually does genetic testing on your melanoma cells. This helps them decide which type of biological treatment might help you.

Drugs that target gene changes (targeted treatments)

The doctor looks to see if the melanoma cells have changes (mutations) in certain genes, such as the BRAF V600 gene. About 40 to 50 out of every 100 people with skin melanoma (40 to 50%) have this gene change. The change to the gene causes it to make an overactive BRAF protein. This makes cells grow and divide too fast.

Targeted treatments that stop cells producing the BRAF protein and can slow or stop the growth of the cancer include vemurafenib (Zelboraf) and dabrafenib (Tafinlar). These drugs are not likely to work in people who don't have the BRAF gene change.

Your doctor will talk to you about which treatment is best for you.

Drugs that help the body's immune system (immunotherapy)

Immunotherapy is a type of biological therapy that helps the body's natural defence system (immune system) to find and destroy melanoma cells.

The immunotherapy drugs for melanoma are:

- ipilimumab
- pembrolizumab
- nivolumab

Doctors used to use two immunotherapy drugs called interferon and interleukin 2 to treat melanoma. They don't use these drugs very often any more.

Newer biological therapies for melanoma

Doctors and the HSE are looking at some new biological treatments for melanoma. These include:

- MEK inhibitors, such as trametinib and cobimetinib
- melanoma vaccines, such as T-VEC (Talimogene laherparepvec)

Chemotherapy

You may have chemotherapy to try to control the melanoma by slowing the growth of the cancer cells and so improving your quality of life for a time, but it can't cure the disease.

Doctors usually try using chemotherapy after they have tried other treatments for melanoma as it is not as effective against this type of cancer as it is with others. Today, oncologists have newer forms of biological therapies that are more effective at fighting melanoma than chemotherapy is so they will usually try these first.

You may receive chemotherapy as a tablet that you swallow, or by injection.

The most common chemotherapy drug for melanoma is dacarbazine (DTIC). You get this through a drip into your arm in the oncology day ward. A nurse puts a small tube into one of your veins and connects the drip to it. You usually have this type of chemo every few weeks. The time between one round of treatment and the start of the next is called a cycle. You usually have chemotherapy as a course of several cycles of treatment. Your doctor can tell you about your treatment plan.

Palliative chemotherapy

Chemotherapy to shrink a cancer and control symptoms is called 'palliative chemotherapy'. To be told that treatment will be palliative can be very distressing and sometimes patients can fear that this means that they are at the very final stages of life. However, ideally palliative care is in place early in a patient's treatment plan as it has been shown to help patients live comfortably for longer and with greater dignity. If you have any concerns or fears, talk to your nursing and medical team.

If the first type of chemotherapy you have (called 1st-line treatment) does not control your cancer, you can usually have a different type of chemotherapy (2nd-line or 3rd-line treatment).

Daily life with chemotherapy

Some people find that they can lead an almost normal life during chemotherapy, but others find everyday life more difficult.

You may feel unwell during and shortly after each treatment, but recover quickly between treatments. You may be able to take your chemotherapy as a tablet at home.

Some treatments are harder going than others, and everyone is different. So it is best to do whatever you feel is right for you.

As well as feeling unwell physically, it is not unusual for people to have ups and downs emotionally. It can be difficult coping with a diagnosis of cancer and having treatment. So you may find you have good and bad days. Remember that there isn't a right and a wrong way to be.

Side effects of chemotherapy can include:

- Fatigue;
- Nausea and vomiting;
- Hair loss;
- Being vulnerable to infection;
- Anaemia;
- Bruising and bleeding;
- Pain and inflammation on the inside of your mouth;

- Loss of appetite;
- Skin becomes dry and sore;
- Short-term memory loss;
- Reduced libido;
- Loss of fertility, temporary or permanent;
- Diarrhoea and constipation;
- Depression;
- Hand and foot syndrome;
- Peripheral neuropathy

Deciding about treatment

It can be difficult to decide which treatment to try, or whether to have treatment at all, when you have an advanced cancer. You will need to consider your quality of life while you are having the treatment. The side effects, as well as stresses such as travelling back and forth to the hospital, can have a big effect on your quality of life.

Your doctor will explain what they hope to achieve with the different treatments they offer you. Some people feel they would like to get an opinion from a second doctor before deciding on their treatment. If you would like a second opinion, you can ask your specialist or GP to refer you.

Your doctor will talk to you about all the options. There may be a counsellor or specialist nurse at the hospital you can talk to. You may also want to discuss things with a close relative or friend. It can be helpful to talk over difficult decisions with someone outside your circle of family and friends.

Ask your nurse

If you have questions about your illness or treatment, your Clinical Nurse Specialist can help. He or she will be supporting you through your diagnosis and treatment plan so ask them about any questions or speak to them about any concerns you have.

Supportive personnel

Medical Oncologist

A medical oncologist is a doctor who treats cancer patients with chemotherapy, biological therapies, or other cancer-fighting drugs. Medical oncologists may specialise in treating one or more types of cancer that occur in a specific organ or tissue (such as the liver, lungs, bone, or skin), system (such as the central nervous system, hormonal system, or reproductive system), or region of the body (such as head and neck). The medical oncologist often coordinates the activities of a patient's multi-disciplinary team (MDT).

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. He or she works together with a medical physicist to create an individualised treatment plan for each patient. Some radiation oncologists specialised in treating one or more types of cancer that occur in a specific organ (such as the prostate, lungs, or bone) or region of the body.

Dermatologist

A dermatologist is a doctor who specialises in problems with the skin. Your GP will refer you to a dermatologist if they think that your mole, freckle or skin lesion looks suspicious. Dermatologists can diagnose tumours accurately and tell the difference between benign and cancerous tumours. Surgery is the most common way of treating skin cancer, with the aim of surgery being to fully remove or destroy the cancer and to leave as small a scar as possible. The surgery may be performed by a dermatologist. The type of surgery will depend on the size and location of the cancer.

Dermatology nurse

Dermatology nurses are nurses who specialise in looking after skin conditions. They may undertake a holistic assessment and take patient history from you, perform a skin examination and complete a diagnostic assessment, examine your regional lymph nodes and use assessment and monitoring tools. Some dermatology nurses perform some surgical procedures.

Specialist surgeons

These 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.

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.

Oncology liaison nurses

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

- Psychological;
- Emotional; and
- Information.

They work with you in the:

- Inpatient oncology unit;
- Oncology day unit; and
- Throughout the hospital with people who 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 provide outreach support to patients at home and help patients who need referral to specialist services.

Public Health/Community Nurse

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.

Psycho-oncologists

The psycho-oncology service is usually part of the psychological medicine service which 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 at the end of this section.

Palliative specialists

As mentioned earlier, 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.

In short, a palliative care specialist can help to relieve pain and other troubling symptoms and meet your emotional, spiritual, and practical needs.

A primary concern for many people with advanced cancer is to have a peaceful and pain-free death and this is something that palliative specialists can help with, planning care and treatment with you and your loved ones. This can help make the thought of death far less frightening.

Your GP, district nurses, and hospital doctors and nurses will also all try to control any symptoms that you have and keep you as comfortable as possible. This can be in the hospital setting as well as at home. The Irish Cancer Society has a night nursing service which provides end of life care for cancer patients and their families in their own home. This service can provide support and rest for your family during this difficult time. Ask your palliative care nurse about this service and make it part of your plan.

The palliative care team work together to give you relief from pain and other symptoms of your cancer. They will offer you a support system that aims to allow you to live your life as fully as possible until you die. They will also support your friends and relatives to help them cope during your illness, and after you die.

Palliative care involves caring for your physical, emotional, psychological, and spiritual needs in the best way possible. The palliative care team is made up of:

- Specialist doctors and nurses;
- Social workers;
- Volunteers;
- Pastoral care workers; and
- Other health care professionals, such as dieticians, physiotherapists and counsellors.

Counselling organisations

Coping with a diagnosis of cancer can be very difficult and very 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 experience 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 on pages 35 in this booklet.

Designated Cancer Centres and cancer support centres

Cancer treatment works best when the treatment team deals with large numbers of cases. This is why cancer care is mainly delivered in eight hospitals around Ireland. These hospitals can provide very specialised care for your type of cancer.

On the next pages you will see contact details for these Designated Cancer Centres; and for cancer support centres around the country.

Ireland's eight Designated Cancer Centres			
Area	Cancer Centre	Phone	HSE Region
Dublin North East	Beaumont University Hospital; www.beaumont.ie/oncology	Main switch: 01-809 3000	HSE Dublin – North East
Dublin East	Mater University Hospital; www.mater.ie	Oncology: 01-803 4447	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 Stoma care: 01-410 3899	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/waterfordregional/	Main switch: 051-848 000	HSE South
West/Northwest	Galway University Hospital http://www.saolta.ie/	Main switch: 091-524 222	HSE West
	Satellite: Letterkenny General Hospital; www.hse.ie/go/LGH/	Main switch: 074-912 5888	HSE West
Midwest	University Hospital Limerick; www.hse.ie/eng/services/list/3/hospitals/ulh/uhl/	Main switch: 061-301 111	HSE West

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Leinster			
ARC House	65 Eccles Street, Dublin 7	01-830 7333	info@arccancersupport.ie
Arklow Cancer Support Centre	25 Kings Hill, Arklow, Co Wicklow	085-110 0066	arklowcancersupport@gmail.com
Cancer Support Sanctuary LARCC	Coole Road, Multyfarnam, Mullingar, Co Westmeath	1850 719719/ 044-937 1971	info@cancersupport.ie
Cois Nore – Kilkenny Cancer Support Centre	Walkin Street, Kilkenny, Co Kilkenny	056-775 2222	coisnorekilkenny@gmail.com
Dochas Offaly Cancer Support	Teach Dóchas, Offaly Street, Tullamore, Co Offaly	057-932 8268	info@dochasoffaly.ie
Gary Kelly Cancer Support Centre	George's Street, Drogheda, Co Louth	041 9805100	phil@gkcancersupport.com
Greystones Cancer Support	La Touche Place, Greystones, Co Wicklow	01-287 1601	info@GreystonesCancerSupport.com

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Hope Cancer Support Centre	22 Upper Weafer Street, Enniscorthy, Co Wexford	053-923 8555	info@hopesupportcentre.ie
Midland Area Cancer Support Centre	Cancer Support Sanctuary LARCC, Coole Road, Multyfarnham, Mullingar, Co Westmeath	044-937 1971	info@cancersupport.ie
Purple House Cancer Support Bray	Aubrey Court, Parnell Road, Bray, Co Wicklow	01-286 6966	info@purplehouse.ie
The Cuisle Centre	Cancer Support Service, Block Road, Portlaoise, Co Laois	057-868 1492	cuislecentre@eircom.net
Connaught			
Mayo Cancer Support Association	Rock Rose House, 32 St Patrick's Avenue, Castlebar, Co Mayo	094-903 8407	info@mayocancer.ie
Sligo Cancer Support Centre	44 Wine Street, Sligo, Co Sligo	071-917 0399	scsc@eircom.net
East Galway and Midlands Cancer Support Centre	Le Cheile, Brackernagh, Ballinasloe, Co Galway	090-964 2088	info@egmcancersupport.com

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Clare Cancer Support Centre	Kilnamona, Ennis, Co Clare	1850 211 630	admin@clarecancersupport.com
Munster			
Cancer Information and Support Centre	Mid-Western Cancer Foundation, Dooradoyle, Limerick	061 210979	maria.keane@hse.ie
Cork ARC Cancer Support House	Cliffdale, 5 O'Donovan Rossa Road, Cork	021 4276688	ellen@corkcancersupport.ie
South Eastern Cancer Foundation/The Solas Centre	The Solas Centre, Williamstown, Waterford	051-304 604	info@solascentre.ie
Suir Haven Cancer Support Centre	Clongour Road, Clongour, Thurles, Co Tipperary	050 – 421197	suirhaven@gmail.com
Ulster			
Donegal Action for Cancer Centre	Moneygreggan, Newtowncunningham, Lifford, Co Donegal	074-912 8400	holmes.betty@gmail.com

Feelings and emotions

There's no right or wrong

There is no right or wrong way to react when you are told your cancer is too advanced to cure. Everyone responds in their own way. For most of us, of course, this is very shocking news. Even if you thought it might happen, hearing it from your doctor can still be devastating.

Some people become silent. They cannot believe what they are hearing and don't know what to say or do. Some start to cry and feel as though they won't be able to stop. Others may become very angry and scared. Some people feel numb and as though they have no emotions. These are all very common reactions. You might find that many questions come into your mind. Why me? Do I deserve this? Why can't you find a treatment to help me? There must be something that will stop this cancer – can't you just try anything?

It is natural to feel desperate, upset, angry, or that you don't believe the news. Be sure to give yourself the time and space to take in what is happening. You may want to be on your own. Or you may need to spend time with your partner, family or friends to help you deal with the news. Of course they may also be very upset and feel that they don't know what to say. Even if all you can do at first is get upset together, that can be a huge help.

You may find that you have different feelings from other people with cancer. Everyone is different and you will deal with things in your own way, so you can take what you need to help you from this section. Ignore anything that doesn't seem to apply to you or help you.

Shock

Shock is often the first reaction when a doctor tells someone they have life-threatening 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. You may remember small amounts of information but do ask again if you cannot remember details. 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 overwhelmed 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 makes your overall situation even worse, you may need professional help from a psychologist or counsellor.

Sharing your feelings

Sharing your fears and sadness with people you love and trust may be a great relief for you. Many people say that talking about their feelings helps them to cope. It also helps your friends and family to understand more about your situation. In turn, this will help them to help and support you. Other people find sharing their thoughts and emotions too difficult, and would rather keep things to themselves. It is important to do whatever feels best for you.

Don't let other people pressure you into talking if you don't feel ready. This is a very personal, emotional time. You can choose how you handle things. If you would like to talk, make sure you choose people you can talk to easily, who will understand how you feel and be able to support you.

If, after some time, you still feel overwhelmed and that you can't cope, try speaking to someone outside your immediate family and friends.

If you are by yourself

If you don't have people nearby to help with practical things, you can ask for help. One of your health care team may be able to arrange volunteers to help out at home, or come to visit you in hospital. Ask your specialist cancer nurse or doctor about this.

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. If they don't talk about it, they can try to 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 okay. It can be a relief for them to be able to cry and say if they are finding things difficult.

Your feelings when you have advanced cancer

If your cancer is very advanced and you are facing the possibility of dying, all these feelings are likely to be very intense.

Understanding your feelings

Having negative feelings is very normal especially at diagnosis and 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. Having an open and frank discussion can help some people to become closer, more understanding and are therefore in a position to support you even more.

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 and give you support.

It is also worth finding out what support is available at your local hospice. Going to a hospice does not mean that you are about to die. Hospices offer skilled, compassionate care for people of all ages in calm, comforting environments. They often have lovely grounds and tranquil gardens. Many hospices offer all sorts of help to people with advanced cancer. This includes:

- Complementary therapies;
- Counselling; and
- Short stays to give you and your family a break (respite care).

To be admitted to a hospice or to access hospice home care, a patient must be referred by their GP or hospital consultant. If the matter has not yet been raised and you are wondering about it, don't be afraid to bring it up yourself with your doctor or nurse. Hospice care is provided free of charge, regardless of the patient's circumstances. Where patients have private medical insurance, their insurer may be asked to contribute towards the cost of their care.

Support outside the family

In the section 'Supportive personnel,' on page 25 there is information about psycho-oncology and complimentary therapists at cancer support centres in Ireland. If you would like to talk to someone outside your own friends and family, look at this section.

A mindful journey with cancer- John's story

In June of 2016, John and his wife were looking forward to celebrating their 50th wedding anniversary when he noticed a small growth on his forehead. Within three days, John was told that he had a rare form of melanoma on his head and neck and was scheduled for emergency surgery. Here, he tells his story, and how he uses mindfulness to weather the storm.

Looking back, I can't believe I was so naïve about melanoma and how serious my diagnosis was. When my surgeon told me that he had removed the melanoma from my head and neck but that the cancer had spread to my lung, I didn't grasp the implications and asked if I could still play in a golf competition that weekend. He gently told me I had a bigger challenge ahead.

Within a week, I was transferred to a centre of excellence in Dublin where, following a week of tests, my oncologist gave my wife and me an overview of my treatment plan. I had a large tumour on my left lung as well as some small lesions. I was put on intense chemo treatment over 12 weeks and then had scans to assess the results. I was told about the multiple side effects I may experience. All of a sudden, the seriousness of my illness hit me like a hurricane. This wasn't helped by the statistics I was reading online. I was somewhat calmed by my doctor's positivity but I felt like I was a ship that was heading for the rocks and that I had no power to change course. The one thing many of us fear in life is to be told that you have Stage 4 cancer and this was exactly the situation I now found myself in. I could feel the negativity rushing through me.

I had been sick once before and found the experience extremely frightening. It had shattered my confidence and left me suffering flashbacks. However, a friend suggested mindfulness which had helped me to gradually recover and so, unexpectedly, my first brush with sickness prepared me for the second.

My treatment is now in its second phase and my tumour is shrinking, though still here. Once I accepted that I had advanced cancer, I realised I had a choice. I could either be swept into a sea of despair or apply myself to navigating my way through the storm with my own compass. I chose the latter. Mindfulness played a significant role in this and I owe a huge debt to my mindfulness teacher who has taught me a whole new way of thinking and coping. I realised that the more I relax and live in the here and now, the more chances I give my body to heal.

I now do 20 minutes of mindfulness each day. Most importantly, I use my breathing as an anchor throughout the day to bring me back into the moment. I don't always do this perfectly. It takes a lot of practice, but I am getting so many benefits from it.

I now think of the negative chatter that goes on in my mind as just that- chatter. It is not real or based on facts. The chatter will pass like swirling dark clouds if I choose to let it and refocus my mind to the centre. Through breathing exercises, I am able to concentrate on the process rather than the outcome. I move from my head to my heart which I have discovered is really the hub of a person. This puts my mind at rest and means I am no longer agitated by negative thoughts.

I want to share my story because I have felt overwhelmed at times but mindfulness has helped me weather this storm. I hope that reading this might help someone in the same position. There are lots of ways to start mindfulness- books, information online and lots of cities and towns have mindfulness courses these days. Mindfulness is not always easy- it takes a lot of concentration and practice- but it has certainly kept me on an even keel through this difficult journey. There is nothing more important in life than living life and, through mindfulness, you can get back to doing this again.

Diet and nutrition

Good nutrition is important during your cancer journey. However, the cancer itself and its treatment can mean that the pleasure nourishment that 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 wellbeing.

It is always a good idea to speak to a dietician about your own specific dietary needs when you are on treatment. Dieticians 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” which you can order 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.

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. Some foods are known to have anti-inflammatory properties. These include:

- tomatoes
 - olive oil
 - green leafy vegetables, such as spinach, kale, and collards (a type of cabbage)
 - nuts like almonds and walnuts
 - fatty fish like salmon, mackerel, tuna, and sardines
 - fruits such as strawberries, blueberries, cherries, and oranges
-
- Foods that are known to be inflammatory are refined carbohydrates, such as white bread and pastries, chips/french fries and other fried foods, fizzy drinks, red meat (burgers, steaks) and processed meat (hot dogs, sausage), margarine, shortening, and lard.
 - Well-seasoned- 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 phytonutrients 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. Phytochemicals 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, and green vegetables, legumes, nuts, tea, and whole grains.
 - Mostly whole foods – processed foods like ham, sausages and burgers and those that are high in fat like French fries and cakes are linked with cancer. 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:

- 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.
- Keep hot foods hot and cold foods cold. Put leftovers in the refrigerator as soon as you are done eating.
- 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.”
- 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 raw fish or shellfish, such as sushi and uncooked oysters.
- Check ‘use by’ and ‘sell by’ dates and do not use foods that are out of date.
- Do not eat at buffets, salad bars, or self-service restaurants.
- Do not eat foods that show signs of mould. This includes mouldy cheeses such as blue cheese.

Coping with symptoms and side effects

People with advanced melanoma can have different symptoms depending on where in the body it has spread to. In some cases, your treatment may also lead to side effects. It is possible to control many of these, so please speak to your medical team so that they can help.

Fatigue

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%). Many people with cancer 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.

- Try not to rush – plan ahead where possible.
- Allow plenty of time for travel, and avoid the rush hour if possible.
- Put chairs around the house so that you can easily stop and rest if you need to.
- Sit down to dry off after your bath or 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).
- 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.
- 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.
- Use a duster on a long stick and sit to do dusting.
- Write a shopping list and go when the shops are quiet; or do your grocery shopping online.
- If you have children, play games that you can do sitting or lying down – reading, puzzles, board games or drawing.
- Ask family and friends for help with shopping, housework or collecting the children from school.
- Have plenty of nutritious snacks and drinks in, so you can have something quickly and easily whenever you feel like eating.
- Don't forget to do things that you enjoy – it will take your mind off your cancer and make you feel more relaxed.

Pain

You might have pain in the area of the cancer but not everyone does. Painkillers can usually control pain well. There are many different painkillers and ways of taking them. Your doctor and nurse can help you to be pain free most of the time. As your medical team:

- What can be done to relieve my pain?
- What types of painkillers are best for me?
- Do these drugs have any side effects?

You and your friends or relatives can do things to help reduce the pain. Complementary therapies such as relaxation and massage can help.

Bowel problems

Bowel problems such as diarrhoea or constipation can be caused by cancer. They can also be caused by treatments or medicines. For example, painkillers commonly cause constipation.

Talk to your doctor or nurse if you have bowel problems. They can help by giving you medicine. And they can refer you to a dietitian for advice on what to eat or drink.

Nausea

Nausea, or feeling sick to your stomach, is a common side effect of cancer treatment. Nausea can have other symptoms that happen at the same time, such as increased saliva (spit), dizziness, light-headedness, trouble swallowing, skin temperature changes, and a fast heart rate. Anti-sickness medicines can usually help to control this. There are different types of anti-sickness medicine and they work in different ways.

Tell your doctor or nurse if you still feel sick so they can find a medicine that's right for you. Tell them what helps and what makes the sickness worse.

Sickness is sometimes caused by fluid building up in the stomach. Putting a tube into the stomach to drain this fluid can ease the sickness and help you feel better. This would be carried out in a hospital.

Below are some tips that help to reduce sickness:

- Eat several small meals and snacks each day if possible.
- Don't drink much just before eating.
- Relaxation techniques help some people control their sickness.
- Ginger can help - try it as crystallised stem ginger, ginger tea or ginger ale.
- Try sipping fizzy drinks.
- Drink high calorie drinks if you can't eat.

If your nausea leads to vomiting, make sure that you let your medical team know if any of these happen:

- You can't keep fluids down
- You can't take the medicines you need
- You're vomiting for 24 hours or longer

Feeling breathless

You might feel breathless if your cancer has spread to your lungs or if you have low red blood cell levels (anaemia). You can learn breathing techniques that can help. You might need a blood transfusion to give you red blood cells if you have anaemia.

Tell your doctor or nurse if you feel breathless. They can prescribe medicines to make your breathing easier.

Swollen tummy

You might have a swollen tummy (abdomen) if your cancer has spread to the liver. The swelling is due to a build up of fluid called ascites. It can make your clothes feel tighter. Your tummy might feel bloated. You might also find it difficult to sit comfortably or to move around. There are other reasons why people develop swelling. But if you notice any swelling that does not go away contact your doctor.

Your doctor can drain off the fluid by putting a small, flexible tube into the abdomen. This helps you to feel more comfortable.

Lymphoedema

The most common symptom if cancer has spread to the lymph nodes is that they feel hard or swollen. Swollen lymph nodes in the neck area can make it hard to swallow.

Cancer cells can also stop lymph fluid from draining away. This might lead to swelling in the neck or face due to fluid buildup in that area. The swelling is called lymphoedema.

Lymphoedema can affect you practically, physically and emotionally. Remember that although lymphoedema usually can't be cured, it can be well controlled. And there are ways of managing it in your daily life so that it becomes part of your daily routine. A healthy well balanced diet helps to keep you well and maintain a normal weight. This can make it easier to manage your lymphoedema.

lymphoedema may affect how you feel about yourself and your appearance. You may find it difficult when meeting new people. They may ask about the swelling or may notice your sleeve or stocking. It can help to think beforehand about what you want to say if someone asks you questions about the lymphoedema. Remember that you have control and it is up to you how much you explain.

Some people find it helpful to talk to other people with similar experiences. Not everyone wants to do this. But if you do, a number of organisations can put you in touch with other people with lymphoedema.

Weakness in your legs or loss of bladder/bowel control

If your cancer has spread to your spinal bones, it can cause pressure on the spinal cord. If it isn't treated, it can lead to weakness in your legs, numbness, paralysis and loss of bladder and bowel control (incontinence). This is called spinal cord compression. It is an emergency so if you have these symptoms, you need to contact your cancer specialist straight away or go to the accident and emergency department.

Physical activity

The importance of being active

Marie Murphy, former Irish Olympian, and consultant exercise and nutrition specialist, has done extensive research into the effect of exercise during and after treatment for cancer. The research shows that exercise helps boost your immunity, which helps your recovery. Exercise along with proper nutrition and good sleep are essential to maintaining your wellbeing. Be sure to speak to your medical team before starting any exercise and keep them informed of how you are getting on.

“The most important thing is to stay active both during treatment and after treatment, within the ability of the individual and how they are feeling,” says Marie.

If someone is enduring the side effects of their treatment, the last thing they may be thinking about is exercise. However, if you are exercising, even in the most gentle way, you can improve how you are feeling, your quality of life, your self-esteem, lower the risk of being anxious and depressed, lessen nausea and lessen the symptoms of tiredness and fatigue. Exercise will counteract the fatigue that most cancer patients feel during treatment. During treatment the amount of exercise is down to the individual and the energy levels that they have.

Even if you are in bed, it is still possible to do gentle exercises, moving your legs, ankles, arms and wrists. This can help to reduce the risk of clot formation, improve your circulation and prevent your joints from becoming stiff.

Nutrition is equally important, though this can be difficult to maintain because of side-effects. You may find it hard to eat your daily allowance of calories, protein and other nutrients. You may need to take a protein supplement while you recover from treatments. You may find it helpful to speak to a dietitian if you are concerned about your dietary intake and/or your weight.

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;
- The Drug Payment 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

Your illness may mean you are entitled to a Medical Card. You can apply for a Medical Card online at:

- www.ssps.ie/portal/medapponline/

People who hold a Medical Card are entitled to a range of Health Services free of charge.

To apply for a Medical Card, you can download and print an application form from this website, fill it in, and return it to the HSE Client Registration Unit, P.O. Box 11745, Dublin 11.

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 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 a €75 a night charge up to a limit of €750 in a 12-month period. Higher rates apply for semi-private or private care. If you do not have a medical card, you may have to pay some in-patient and out-patient hospital charges. You may be entitled to some community care and personal social services.

Mortgages, loans, pensions and insurance

Mortgages and loans

You may be experiencing short-term 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, 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. 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.

Pensions

You may be worried about taking a break from paying into a private or occupational pension scheme. For information about your scheme, contact:

- The trustees in an occupational (workplace) pension scheme; and
- The provider in a private scheme.

They will tell you if the scheme allows you to take a break and how this may affect your final pension payout.

The Department of Social Protection can tell you how a break in employment may, or may not, affect your final state pension. See more information on their website at:

- www.welfare.ie/en/Pages/home.aspx

Health insurance

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

Financial implications: useful contacts

	Phone	Website
Medical card forms	Phone HSE customer care team at the Client Registration office Call Save 1890 252 919	www.sspcrs.ie/portal/medapponline/
Free advice, Money advice and budgeting service (MABS)	0761 07 2000	www.mabs.ie
Citizens' information Service	0761 07 4000	www.citizensinformation.ie/en/

Planning ahead

You can read more about planning ahead for financial matters as well as other legal, practical and medical matters in the section starting on page 51.

Comfort Fund

The Marie Keating Foundation provides financial support to cancer patients who are going through treatment and find themselves in financial difficulty. Further details are available on page 70.

Coping with terminal illness

Finding out you have advanced cancer

When cancer is advanced it means that it can't be cured and is likely to cause death within a limited period of time. The amount of time is difficult to predict, but it could be weeks to several months or even longer. Doctors might also say that the illness is 'terminal'. This distressing news can affect you and the people close to you in different ways.

If you don't feel like talking straight away, just tell the people around you. As hard as it can be, try not to push your emotions aside completely. If you can manage it, it is better to express how you feel and allow your emotions to come to the surface – even if that is uncomfortable and hard to cope with.

Feelings you may have

Over the first few days, you may go through a range of very strong emotions. The emotions may change very quickly and sometimes you may feel numb or as though everything is happening to someone else. Some people say they feel very calm and detached when they are first told they don't have long to live.

At times, you will probably feel shock, anger, and sadness. These emotions can feel overwhelming at times. This news will mean that you can't plan your future in the way you had hoped. Dying may mean leaving behind a partner, children, and other important people in your life. You may wonder how they will cope and won't want to see them upset.

These thoughts may be too painful to cope with at times. You might feel as if you are going mad. You may be unable to stop crying and worrying. All this is perfectly normal and understandable.

You may find it difficult to look around and see life going on as normal for most people. It can feel very strange to watch people going about their daily lives as usual – shopping, driving and working. Coping with this roller coaster of feelings can be very exhausting. You may feel as if you are stuck under a huge black cloud and that there is no point in doing anything. Most people will have some or all of these emotions. This usually changes gradually. Many people say that the intensity and distress lessens in time. This doesn't mean that you stop worrying or feeling upset. But the feelings get more bearable. You will most likely be able to think about your situation a little more calmly and plan what you want to do.

Talking about dying

Sharing your fears and sadness with people you love and trust may be a great relief for you. Many people say that talking about their feelings helps them to cope. It also helps your friends and family to understand more about your situation. In turn, this will help them to help and support you. Other people find sharing their thoughts and emotions too difficult, and would rather keep things to themselves. It is important to do whatever feels best for you.

Don't let other people pressure you into talking if you don't feel ready. This is a very personal, emotional time. You can choose how you handle things. If you would like to talk, make sure you choose people you can talk to easily, who will understand how you feel and be able to support you. You may have different types of conversations with different people, depending on your relationship with them. With some people, you may have an in-depth, serious discussion while with others you might have a more open discussion while watching TV. You can decide based on what makes you comfortable.

If, after some time, you still feel overwhelmed and you can't cope, try speaking to someone outside your immediate family and friends.

If you are by yourself

If you don't have people nearby to help with practical things, you can ask for help. One of your health care team may be able to arrange volunteers to help out at home, or come to visit you in hospital. Ask your specialist cancer nurse or doctor about this. If you need help with personal care, such as washing or dressing, social services may be able to help. They can arrange a care package for you.

You may be wary of letting people you don't know into your life, but most people find that they do need support at some stage from other people or organisations. The people that you are put in touch with will be understanding and aware of your feelings and need for personal space. They will want to support you in the best possible way they can.

You might find help and support at your religious organisation or through other organisations you are involved with.

Difficult questions and important decisions

It can be helpful to find out what support is available. Some people want to make plans about what they would like to do before they die. You may like to ask your doctor about:

- How to control cancer symptoms;
- What is likely to happen; and
- Who to talk to about your concerns.

Having some idea about what to expect can help you feel less anxious. You may also want to think about where you want to be at the end of your life.

What happens in the final days

Knowing that you, or a loved one, is close to dying can be very difficult for everyone involved. People often ask questions about how someone will die, especially relatives and friends. They often worry that they will not be able to cope, or know what to do when the person they are caring for dies.

It is very difficult to give exact details of how someone will die. Each person is different and will die in their own unique way, but here is some general information about what may happen and what a carer can do to support you through the process of dying.

Physical changes

The body begins its natural process of slowing down all its functions. How long this takes varies from person to person – it may take hours or days. The dying person will feel weak and sleep a lot. When death is very near the dying person may have:

- Sleepiness and difficulty waking (semi-conscious);
- Difficulty swallowing or not wanting to eat or drink at all;
- Loss of control of bladder and bowel;
- Restless movements;
- Changes in breathing;
- Noisy breathing;
- Confusion and disorientation;
- Complete loss of consciousness.

For carers, it can be emotionally very difficult to watch someone go through these physical changes. But they are part of a natural dying process and don't mean that the person is uncomfortable or in distress.

The doctors and nurses looking after you during this time will be checking regularly for these changes. They will do all they can to make you as comfortable as possible during your death. If you are being looked after at home while you are dying, your carer should have support from a specialist palliative community nurse, district nurses, and the GP. They can answer their questions and help to make home nursing easier.

Sleepiness and difficulty waking (semi-conscious)

People who are dying often sleep a lot and may not respond when someone tries to wake them. But this doesn't mean they can't hear someone talking to them. Hearing may be one of the last senses to be lost. So it is important that people continue to talk and comfort you.

They can sit close to you and hold your hand. They should not say anything to you that they would not want you to hear. It's also a good idea for them to tell you when they enter or leave your room.

Difficulty swallowing or not wanting to eat or drink at all

There will come a time when you will not want to eat or drink anything. It is important that no one tries to force you to eat or drink. This would make you uncomfortable. If you are still awake people can give you small pieces of ice to suck or sips of fluid to keep your mouth moist. They can put vaseline or lip balm on your lips to help stop them getting dry and sore.

If you really can't take anything into your mouth, your carer can moisten your lips and mouth every 1 to 2 hours with lemon and glycerine swabs or water. Your GP or community nurse can get you the swabs.

Loss of bladder and bowel control

The dying person may lose control of their bladder and bowel. This happens because the muscles in these areas relax and don't work as they did. The nursing staff will do all they can to protect the bed and keep you as clean and comfortable as possible.

If you are being cared for at home, the district nurses and specialist nurses can arrange for your carer to have draw sheets or pads to protect the bed. They may also be able to arrange a laundry service for you, if necessary. As people become very close to death and are not eating or drinking, the amount of urine and stools they produce gets less and less. Some people have a tube inserted to drain the bladder which makes them more comfortable. If this is needed, the GP will organize it.

Restless movements (as though in pain)

Many people who are dying, and the people around them, worry that they will be in pain. Not everyone dying of cancer has pain. But if they do, it can usually be well controlled and people can be kept very comfortable. The doctors and nurses looking after the dying person will do all they can.

Sometimes restlessness is a sign of being in pain. If you can't communicate very well and your carer thinks you are in pain, the most important thing they should do is to tell your doctor and nurses. They will want you to be pain free, so your carer should talk to them. This will help them plan the best way of controlling the pain and keep you comfortable.

Changes in breathing

When someone is dying their breathing often changes. It may become noisy and irregular. There may be times when they stop breathing for a few seconds. This is called Cheyne Stoke (pronounced chain stoke) breathing. They may breathe with their mouth open and use their chest muscles to help them catch a breath.

It can help if your carer raises the head of the bed with pillows or cushions. Just sitting with you, speaking gently, and holding your hand can be very reassuring for you. If someone is having difficulty breathing, a doctor or nurse may suggest giving a small dose of morphine, even if they are not otherwise in pain. Morphine can help to make breathing easier.

Noisy breathing

You may make gurgling or rattling sounds as you take each breath. This is coming from your chest or the back of your throat. It is because there is a buildup of mucus and saliva and you don't have a strong enough cough reflex to cough it up. If your carer raises your head and turns it to the side, gravity may help to drain the secretions. Sometimes the fluid can be sucked out through a thin tube put down into your windpipe, but this is not usually needed. Medication can help to relieve this also, so your carer can let the nurses know. Hearing these gurgling sounds can be upsetting for your carers, but they do not usually seem to cause distress to the dying person.

Cold feet, hands, arms and legs

The dying person's face, hands, arms, feet and legs often become cold to touch. Their skin may also become pale and look blotchy or mottled. This happens because there is less blood circulation to these parts of the body. Your carer should keep you warm with blankets, but they shouldn't use an electric blanket as this may become too uncomfortable. Thick socks can help to keep your feet warm. The room shouldn't be overheated as this can make it stuffy. It should just be kept at a comfortable temperature.

Confusion and disorientation

Your carer may hear you say things that make no sense. You may not know what day it is or may not appear to know who your carer is. You may even say things that are totally out of character. For example, you may shout at your carer or physically push them away. This can be very hurtful and upsetting. But your carer will know that you don't mean it and are not aware that you are doing these things.

This happens partly because of the chemical changes going on inside your body.

Complete loss of consciousness

At the end of life, the chemical balance of the body becomes completely upset. The dying person then slips into unconsciousness. This is usually right towards the end, maybe only a few hours or days before death. Breathing becomes irregular and may become noisy. Your carer won't be able to wake you at all. Your breathing will stay irregular for some time and will at some point stop.

Emotional and spiritual changes

Everyone will feel different emotions when they are dying. A lot will depend on:

- The type of person you are;
- Your age;
- How much support you have;
- Your religious and spiritual beliefs; and
- The experiences you have had in life.

Someone dying in their 20s is likely to feel very different to someone who is 80. If the person dying is leaving behind young children, they will have different worries from someone whose children are grown up and able to take care of themselves.

Before the final stages of death you may want to complete any unfinished business. This may mean:

- Sorting out any problems with personal relationships, or deciding not to;
- Visiting certain places;
- Buying gifts for people;
- Sorting out personal belongings and giving special things away to family and friends;
- Getting your will and financial business in order; and
- Seeing a religious leader.

As death gets closer you may begin to let go and seem more at peace with things. Others may become very anxious, fearful or angry. Some people may appear to withdraw even from the people they love and care about. But this doesn't mean that they don't care anymore. These events are all very normal and a natural part of dying.

Even if the physical body is ready to shut down, some people may resist death. You may still have issues you want to resolve or relationships you want to put right. It is important that your loved ones let you know they are there for you and will help you with any of these issues.

You and your relatives and friends are likely to feel some very strong emotions during the time you are dying. Often all people can do is to give you a lot of support and comfort during this difficult time. Friends and relatives should:

- Allow you to share any memories or feelings you have; and
- Reassure you that it is all right to let go and die whenever you are ready.

Some people who are dying will hold on until people close to them say it is alright to go whenever they are ready. So letting you go can be one of the most important and loving things they can do for you.

If those close to you need some support when you are dying it may help them to speak to:

- The doctor or nurses on the ward;
- A religious leader;
- A counsellor;
- Close friends and relatives; or
- The palliative care team if at home

Your carers should try not to worry that they are going to do the wrong thing. Just being with you and letting you know they love and care for you is the most important thing.

Planning for end of life

It can be upsetting to think about the future when you have advanced cancer. However, many people find it gives them peace of mind to have medical plans in place and legal and practical matters in order, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not. These are ways for you to lessen decision-making burdens on your family, and for you to know that your wishes will be respected.

‘Think ahead’

You may want to talk to your solicitor about appointing one person to manage your financial affairs on your behalf.

The ‘Think ahead’ form allows you to fill in details about:

- Bank accounts;
- Insurance policies – home, property, car etc;
- Life assurance;
- Credit cards;
- Tax affairs;
- Pensions;
- Mortgage documents;
- House deeds;
- Other assets; and
- Any debts.

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.

'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 are so ill that you cannot speak for yourself. It allows you to set out your preferences about medical treatments 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 as 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 free 'Think ahead' form to fill in your preferences at:

<http://www.thinkahead.ie>

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.

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, your home, a family member's home, 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 see:

Website: www.hospicefoundation.ie

Phone: 01-679 3188

Email: hfh@hospicefoundation.ie

Digital accounts

Email accounts, social networking profiles and photo sharing are seamlessly integrated into many of our everyday lives. Things like digital music libraries and photo albums may not translate to a euro amount but are certainly valuable so creating a plan for these assets is important. Consider making a password-protected list of your online accounts, that includes all the user identification, passwords, and account numbers. If you choose, you can provide the executor of your will with the instructions on where to obtain your password list and what should be done with it. Alternatively, you can give the list to a family member or friend that you trust and give them instructions on what to do with it. If you are on Facebook, you can pick a beneficiary of your Facebook account. You can set this up in your general Security setting tab under Legacy Contact. This legacy contact will manage your memorialised Facebook account after you have passed away.

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, 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.

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;
- Ovarian Cancer
- Skin cancer;
- Prostate cancer; and
- Testicular cancer.

We do not receive any Government funding and all of our services are provided free of charge.

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 by sending an email to info@mariekeating.ie or by completing a form online at www.mariekeating.ie/cancer-services.

Our nurse will respond to you in complete confidence to the email address or phone number 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.

The Marie Keating Foundation accepts applications on behalf of men, women and children. In 2016 alone, the Marie Keating Foundation's Comfort Fund helped more than 530 families through their cancer journey.

How does it 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 health care professional involved directly in your care. If you do not know who this is, ask in the hospital or centre in which 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 only provides 'once-off' assistance. The Foundation 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.

Positive Living

The Marie Keating Foundation provides workshops and seminars to help people with metastatic cancer adapt and cope. The Positive Living programme includes advice from experts on issues that people with metastatic cancer often face, including:

- Managing side effects, treatment plans and quality of life
- Changed nutritional needs
- Coping with emotions, feelings and end of life
- Managing stress and physical activity
- Mindfulness and positive appearance
- Sexuality and relationships
- Talking to children about cancer

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

For more information please contact:

Nursing Services Coordinator

The Marie Keating Foundation

Phone: 01-628 3726

Email: info@mariekeating.ie

Notes

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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. The Marie Keating Foundation helps men and women prevent cancer, detect it at its earliest stages and journey through cancer diagnosis, treatment and survivorship.

Through its community information service, the Foundation's nurses have talked to over 230,000 people about the causes and risk factors of cancer. The Foundation offers national awareness and education programmes covering the most common cancers affecting people in Ireland, including bowel, breast, lung, prostate and skin cancer.

Through its Comfort Fund, the Marie Keating Foundation provides financial assistance to people who are receiving treatment for any kind of cancer and who find themselves in financial difficulty as a result. In 2016 alone, over 525 families received assistance from the Comfort Fund.

The Marie Keating Foundation supports cancer survivors through its Survive & Thrive programmes which are run nationwide, free of charge, for men and women who have finished their cancer treatment. Over 600 cancer survivors have attended courses and seminars since 2015.

On 2 February 1998, our mother Marie died from cancer. We started this Foundation with the aim of making cancer less frightening by enlightening. We also hope that other families will not have to go through what we did and to ensure that such a wonderful person did not die in vain.

Take care,



Marie Keating
FOUNDATION

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