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CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING ADVANCED MELANOMA



This booklet is about advanced melanoma. It is part of a series of booklets on melanoma. The other booklets in the series are:

- **Understanding melanoma and treatment with surgery**
- **Understanding melanoma – lymph node assessment and treatment**
- **Understanding melanoma that has come back in the same area**

Check with your cancer doctor or nurse that this is the right booklet for you, and whether you need any other information.

If you would like more information, our cancer support specialists can send it to you. Call them on **0808 808 00 00**.

About this booklet

This booklet is about melanoma that has spread from the original melanoma to other parts of the body. It includes information about how it is diagnosed and treated. It also suggests different ways of coping with advanced cancer.

Melanoma develops from cells in the skin called melanocytes. These cells give our skin its colour. Most melanomas can be successfully treated with surgery. However, sometimes melanoma spreads to a different part of the body, where it can grow into a new cancer (known as a secondary cancer or metastasis). There are different treatments for advanced melanoma.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We cannot advise you about the best treatment for you. This information can only come from your doctor or specialist nurse, who know your full medical history.

This booklet includes quotes from people who have been affected by melanoma. Some are from our online community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)) and others are from people who have chosen to share their stories with us. Some names have been changed. To share your story, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

On pages 89–93, we have listed some useful contact details and other organisations that can help. On pages 94–95, there is space to write down any notes or questions you have.

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

If you find this booklet helpful, you could give it to your family and friends. They may also want information to help them support you.

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What is advanced melanoma?

Melanoma is a type of skin cancer that develops from cells called **melanocytes**. These cells give our skin its colour.

Most melanomas can be successfully treated. However, sometimes melanoma can come back after treatment. This may be only a few months after treatment, but can sometimes be many years after the original melanoma was first removed.

Melanoma can come back very close to where it first started (the original site). This could be in the skin (a local recurrence) or in nearby lymph nodes (a regional recurrence). It can also spread to other parts of the body. This is called **advanced melanoma**. Sometimes melanoma has spread when it is first diagnosed.

This booklet is about advanced melanoma. We have another booklet in this series called **Understanding melanoma and treatment with surgery**. It explains more about the different types of melanoma, causes, risk factors and staging. We have other booklets about treating melanoma that has come back in the same area and about lymph node assessment and treatment. You can order our booklets by calling us on **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Melanoma cells may spread to other parts of the body through the bloodstream or lymphatic system. The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

When cancer cells from a tumour spread to a different part of the body, they grow into a new cancer (called a **secondary cancer** or **metastasis**). A secondary cancer is always known by the area where it first started to grow (the primary site) and is treated as this type of cancer. For example, a melanoma that starts in the skin may spread to the lungs. As the cancer in the lungs is made up of melanoma cells, it is called secondary or advanced melanoma. It is also treated as a melanoma.

In advanced melanoma, the cancer cells have spread to one or more of the following areas of the body:

- lymph nodes far away from the original melanoma
- areas of skin distant from the original melanoma
- the lungs
- the liver
- the bones
- the brain
- the digestive system.

Signs and symptoms

Symptoms of advanced melanoma can begin years after the original melanoma was diagnosed and removed.

A small number of people will develop symptoms of a secondary melanoma who have not had melanoma before. They may have had no previous signs of melanoma and no abnormal-looking moles.

Symptoms of advanced melanoma

The symptoms of advanced melanoma depend on where in the body the melanoma has spread to.

The lymph nodes

If the cancer spreads to lymph nodes, they may feel hard and swollen. Rarely, affected lymph nodes press on tissues or nerves nearby, which may cause pain.

The skin

If secondary tumours occur in the skin, they often appear as firm or hard lumps (nodules).

The lungs

If melanoma spreads to the lungs, it may cause:

- breathlessness
- a cough that does not go away
- pain in the chest
- a build-up of fluid around the lungs (pleural effusion).

We can send you information on secondary cancer in the lungs, pleural effusion and coping with breathlessness. Or you can read about them on our website ([macmillan.org.uk/information-and-support](https://www.macmillan.org.uk/information-and-support)).

The liver

Cancer cells that spread to the liver can cause:

- swelling and discomfort in the liver area (the right hand side of the tummy, under the lower ribs)
- sickness (nausea)
- loss of appetite
- a build-up of fluid in the tummy (ascites)
- yellowing of the skin and eyes (jaundice).

We have more information on secondary cancer in the liver and ascites.

The bones

If cancer spreads to the bones, it can cause bone pain and discomfort. Rarely, the first symptom may be a broken bone (fracture) after a minor injury. This happens because the bone is weaker due to the cancer.

Secondary cancer in the bones of the spine can put pressure on the nerves of the spinal cord. This is called malignant spinal cord compression (MSCC). The symptoms of MSCC may include:

- back or neck pain
- muscle weakness
- numbness and weakness in the legs
- problems with the bowel and bladder.

If you have weakness, pain, tingling or numbness in your legs, it is very important to tell your doctor or specialist nurse straight away so that your symptoms can be checked. The earlier MSCC is diagnosed, the better the chances are of treatment being effective. If you cannot contact your specialist team, you should attend your local accident and emergency department without delay.

We have a booklet called **Understanding secondary cancer in the bone** and a leaflet about MSCC, which you may find helpful.

The brain

Secondary cancer in the brain may cause headaches and sickness, which can often be worse first thing in the morning. The cancer may affect an area of the brain that controls a certain part of the body. This can cause symptoms such as:

- weakness in a limb
- numbness
- tingling or pins and needles.

Sometimes people have seizures (fits) or a change in their personality.

We have more information about secondary cancer in the brain on our website.

The digestive system

If the melanoma spreads to the digestive system, it can cause:

- pain in the tummy (abdomen)
- a change in bowel habit (constipation or diarrhoea)
- sickness (vomiting)
- blood in or on your poo (stools)
- unexplained tiredness.

General symptoms

The general symptoms of advanced melanoma can include:

- weight loss
- loss of appetite
- feeling extremely tired (fatigued).

All the symptoms mentioned here can be caused by other, less serious conditions. If you have any of these symptoms, it is important to let your doctor know.



DIAGNOSING ADVANCED MELANOMA

How advanced melanoma is diagnosed

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How advanced melanoma is diagnosed

If you have been treated for a melanoma before, you may still be attending a clinic for check-ups and possibly scans. Sometimes a recurrence of the melanoma will be found at one of these appointments, before you develop any symptoms. If you notice new symptoms between appointments, you should contact your specialist or GP (family doctor). They will arrange tests to investigate your new symptoms. The tests your doctor arranges will depend on the symptoms you have.

Tests to check your lymph nodes

If you have just been diagnosed with a primary melanoma, you may have tests to check whether the cancer cells have spread to the lymph nodes nearby. You can find out more about tests to check the lymph nodes in our booklet **Understanding melanoma – lymph node assessment and treatment**.

If these tests show that there is cancer in the lymph nodes, or if you have symptoms that suggest the melanoma has spread elsewhere, you may have some of the following tests.

Blood tests

Samples of your blood may be taken to check your general health and the number of blood cells in your blood (blood count), and to see how well your kidneys and liver are working.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection. You'll probably be able to go home as soon as the scan is over.



Someone having a CT scan

Chest x-ray

You may have a chest x-ray to check whether the cancer has spread to your lungs.

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used.

Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Ultrasound scan

Ultrasound scans use sound waves to build up a picture of part of the inside of the body, such as the abdomen, liver or pelvis.

If you have a pelvic ultrasound, you will be asked to drink plenty of fluids so that your bladder is full. This helps to give a clearer picture. An ultrasound specialist will then spread a gel on to your abdomen and gently rub a small, microphone-like device, which produces soundwaves, over the area. The sound waves are converted into a picture by a computer. An ultrasound scan is painless and only takes a few minutes.

Bone scan

A bone scan can show up any abnormal areas of bone. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. This travels around the body and bloodstream. Abnormal areas of bone absorb more radioactivity than normal bone and show up on a scanner.

You will have to wait for up to three hours after having the injection before you have a scan. This is to allow time for the bone to absorb the radioactive substance. It is a good idea to take a book or a magazine with you to help pass the time. After a few hours, you will have a scan of your whole body.

Bone scans cannot always tell whether an abnormal area is due to cancer or other conditions, such as arthritis. Sometimes more detailed scans will be needed, such as CT or MRI scans.

PET (positron emission tomography) scan

A PET scan uses low-dose radioactive sugar to measure the activity of cells in the body. A very small amount of a mildly radioactive sugar is injected into a vein in your hand or arm before you have the scan. Areas of cancer are normally more active than surrounding tissue and absorb more of the sugar, which shows up on the scan.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 89–93 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry). To find details about the cancer registry in your area, see page 91.





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Treatment overview

When a melanoma has spread to other parts of the body, it can sometimes be cured, but this is rare. The aim of treatment is usually to try to control the cancer and help you live longer. It may also help improve your symptoms and quality of life. Controlling the cancer might mean shrinking the size of the tumour or stopping it from growing for a while.

The main treatments for advanced melanoma are:

- **immunotherapy and targeted therapies** (see pages 29–35), which are often used to help control or shrink the growth of advanced melanoma
- **radiotherapy** (see pages 36–38), which helps to control symptoms if melanoma has spread to the brain, liver, bones or skin
- **surgery** (see pages 39–41), which may sometimes be used to remove secondary tumours, or may be used if the spread of the cancer is limited or to help control symptoms
- **chemotherapy** (see pages 42–43).

Other treatments (see pages 44–47) may sometimes be used to treat skin nodules. These include laser therapy, electrochemotherapy and chemotherapy into a limb.

These treatments may be used alone or in combination.

How treatment is planned

In most hospitals, a team of specialists will talk with you about the treatment they feel is best for your situation. This multidisciplinary team (MDT) will include:

- a **dermatologist** – a doctor who specialises in the treatment of skin cancers and skin disorders
- a **plastic surgeon** – a doctor who specialises in reconstructive surgery
- a **specialist surgeon** – depending on what area of your body the cancer has spread to
- a **medical oncologist** – a specialist in chemotherapy
- a **clinical oncologist** – a specialist in radiotherapy, chemotherapy and targeted therapies
- a **pathologist** – a doctor who examines samples from the tumour to see whether it is a cancer and which type it is
- a **skin cancer specialist nurse** – who gives information and support and co-ordinates your treatment.

The MDT may also include other healthcare professionals, such as a palliative care specialist (see page 63), research nurse, dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

The treatment that the MDT think is best for you will depend on:

- your general health
- which part of your body the melanoma has spread to
- your test results
- the treatment you have already had
- your symptoms.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Decisions about treatment

Different treatments can be equally effective in controlling advanced melanoma. In this situation, your doctors may offer you a choice of treatments. If you are asked to make a choice, make sure you have enough information about the different options, what is involved and the possible side effects. This will help you decide on the right treatment for you.

Remember to ask questions about anything that you don't understand or that you feel worried about. It may help to discuss the benefits and disadvantages of each option with your cancer specialist or nurse specialist, or with our cancer support specialists on **0808 808 00 00**. You may also want to read our booklet **Making treatment decisions**.



It is not always clear which treatment is going to be the best. Sometimes you may need to try a treatment for a short time before you and your doctor can decide whether to continue with a full course. For example, if you are having chemotherapy to control or shrink the cancer, you may have a scan after two or three treatment cycles. This gives you and your doctors more information about how helpful the treatment is. If the scan results show it is working, you can carry on with the course of treatment. If the results show the treatment is not helping, you and your doctor can discuss other treatment options.

There may be a time when treatment has little effect on the cancer, and you will get the side effects of the treatment without any of the benefits. Making treatment decisions in these circumstances is always difficult, and you may want to talk about it carefully with your cancer specialist (oncologist), specialist nurse and family.

If you decide not to have any more treatment, you will be given supportive (palliative) care, to control any symptoms. You may be given medicines to control symptoms such as pain or feeling sick (nausea). You might also be given cancer treatments to ease symptoms. For example, radiotherapy can help with pain. If you choose not to have any cancer treatments, you will still be offered palliative care, such as painkillers.

'You are entitled to have these things explained. We have felt confused, but often the answer is to go together (my wife always comes with me) and go prepared. Read as much as you can, seek advice from others where possible and go with a written list of questions.'

Chris

Questions you could ask your specialist

It often helps to take a relative or close friend with you when you go to your hospital appointments. As well as giving support, they may be able to take notes for you, or remind you of any questions you want to ask.

It may help you to make a list of questions before your next appointment. You can use pages 94–95 to write down your questions and the answers you receive. Here are some questions you might want to ask your doctor:

- What are my treatment options?
- Is this treatment aimed at helping me live longer or controlling my symptoms?
- How long will it be before I feel the benefit of any treatment?
- What are the side effects of the treatment?
- Can I carry on working?
- Will I need to stay in hospital and, if so, for how long?

Some people find it useful to record the discussion with their doctor (with their doctor's permission). Recordings can also be helpful for family and friends to listen to, so that you don't have to keep repeating information.

Targeted therapies

Targeted therapies are used to stimulate the immune system or control the growth of cancer cells. They may be called biological therapies.

Different types of targeted therapy may be used to treat advanced melanoma. Some are available on the NHS and others are only used in clinical trials at the moment (see pages 48–50).

If a drug is not routinely available on the NHS, there may be other ways you can get access to it. Your cancer doctor can give you advice.

We can send you more information on what to do if a treatment is not available on the NHS. Contact our cancer support specialists free on **0808 808 00 00**, Monday to Friday, 9am to 8pm. You can also order information online at **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)**

Immunotherapy

Some targeted therapy drugs help the body's immune system to fight cancer. This is known as immunotherapy. There are different types of immunotherapy that work in different ways. The main drugs used to treat advanced melanoma are ipilimumab, pembrolizumab and nivolumab.

Ipilimumab

Ipilimumab (Yervoy®) works by attaching itself to normal T-cells. T-cells are part of the immune system. They fight infection and diseases. In some people, T-cells can recognise and destroy melanoma cells. But a protein on the surface of T-cells, called CTLA-4, stops this happening. Ipilimumab blocks this protein so the T-cells can destroy melanoma cells. It can help to shrink or slow the growth of advanced melanoma.

You have ipilimumab as an infusion (drip) into a vein over about 90 minutes. The infusion is repeated every three weeks. Up to four treatments are given.

Common side effects of ipilimumab include:

- tiredness (fatigue)
- feeling or being sick (nausea or vomiting)
- diarrhoea
- a skin rash
- itching.

Ipilimumab can cause inflammation in different parts of the body, such as the bowel, liver, skin and eyes. This can sometimes cause more serious side effects, including persistent diarrhoea, changes in the way the liver works, skin rashes and blisters affecting several areas of the body, and blurred or double vision.

It is important to report these side effects straight away to your medical team or specialist nurse. If you get these side effects, you will usually be prescribed steroid tablets to help reduce the inflammation caused by the ipilimumab. Depending on the severity of the side effects, treatment may be delayed or sometimes stopped. Your doctor or nurse will give you more detailed information about ipilimumab and its side effects. We can also send you more information.

Pembrolizumab and nivolumab

Pembrolizumab (Keytruda®) and nivolumab (Opdivo®) both target a protein called a PD-1 receptor that switches off T-cells. They attach to the PD-1 receptor so the T-cells can't be switched off. This keeps the T-cells active and may help shrink a tumour or stop it growing.

Both drugs are given as a drip (infusion) into a vein.

Common side effects include:

- tiredness
- diarrhoea
- sickness
- joint and muscle pain
- an increased risk of infection
- an allergic reaction
- a skin rash.

Sometimes nivolumab is given in combination with ipilimumab. Your doctor or specialist nurse will give you more information about these treatments if they are suitable for you. We can also send you more information.

T-VEC

T-VEC (Imlygic®) is a newer immunotherapy treatment that may sometimes be used to treat advanced melanoma. The drug is injected directly into the melanoma. Side effects include headaches, tumour pain, flu-like symptoms and tiredness. Your doctor or specialist nurse will give you more information.

T-VEC may only be available in some situations. Your cancer doctor can tell you if it is appropriate for you.

Cancer growth inhibitors

In order to grow and divide, cancer cells 'communicate' with each other using chemical signals. Cancer growth inhibitors are drugs that interfere with this process and affect the cancer's ability to develop.

You may be offered treatment with a cancer growth inhibitor if your cancer has a specific change (mutation) in a gene called BRAF. BRAF helps to regulate a protein involved in cell growth. About half of all people with melanoma have a BRAF gene mutation. Doctors can tell if you have this mutation by testing melanoma tissue. They will test tissue that was removed during tests to diagnose your melanoma or during surgery.

The main cancer growth inhibitors used to treat advanced melanoma are vemurafenib, dabrafenib and trametinib. They work in different ways and are not effective in people who do not have the BRAF gene mutation.

Vemurafenib

The change in the BRAF gene leads to the production of a changed (mutated) protein. This protein helps melanoma tumours grow. Vemurafenib (Zelboraf®) blocks (inhibits) the changed BRAF protein, which can stop the melanoma cells from growing and dividing.

Vemurafenib is given as a tablet, which is taken daily by mouth. Your doctor will let you know if vemurafenib is a suitable treatment for you.

Common side effects include:

- a skin rash
- a cough
- diarrhoea or constipation
- feeling or being sick
- muscle and joint pain
- headaches
- hair loss
- loss of appetite
- tiredness.



Dabrafenib

Dabrafenib (Tafinlar®) is another targeted therapy drug used to treat melanomas that have tested positive for the BRAF gene mutation.

Kinases are proteins made by cells. They send important chemical signals to cells telling them when to grow. Dabrafenib blocks a faulty kinase, made by the mutated BRAF gene, that tells the cancer cells to grow and divide in an uncontrolled way.

Dabrafenib is given as a tablet, which is taken twice a day by mouth. You have to take the tablets at least two hours before eating or at least one hour after eating. Your doctor will tell you if dabrafenib is a suitable treatment for you.

Common side effects include:

- skin changes
- fever
- a cough
- headaches
- feeling or being sick
- loss of appetite
- diarrhoea or constipation
- muscle and joint pain
- tiredness.

We can send you more information about vemurafenib and dabrafenib.

Trametinib

Trametinib (Mekinist®) is a newer targeted therapy drug used to treat people who have the BRAF gene mutation. The faulty BRAF gene affects a protein called mitogen activated protein kinase (MEK). MEK can make cancer cells divide in an uncontrolled way. Trametinib blocks MEK and can stop melanoma cells growing. It is known as a MEK inhibitor.

Trametinib is taken as tablets, once a day. It may be given in combination with other targeted therapy drugs.

Common side effects of trametinib include:

- a skin rash
- diarrhoea
- high blood pressure
- tiredness
- feeling or being sick.

Your doctor or specialist nurse will give you more information about the possible side effects.

Newer therapies

Newer therapies that block some of the enzymes involved in cell growth are being researched as treatments for advanced melanoma. Research is also looking at using cancer vaccines for advanced melanoma. If there are clinical trials testing these or other drugs, your hospital team will give you more information about them. You can read more about clinical trials on pages 48–50.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is usually given as a series of short, daily treatments in the hospital radiotherapy department, using equipment like a large x-ray machine.

For advanced melanoma, radiotherapy is used to help reduce pain and improve other symptoms. You may need only a few sessions, or a short course of treatment. This type of radiotherapy is called palliative radiotherapy, because it is given to ease symptoms.

Radiotherapy can be used to help improve symptoms when melanoma has spread to different parts of the body:

- **The skin or lymph nodes distant from the original melanoma** – Radiotherapy can help reduce the size of skin nodules or lymph nodes and improve symptoms, such as pain.
- **The bones** – Radiotherapy is the most common treatment for secondary bone cancer. It helps to reduce bone pain and swelling.
- **The brain** – Radiotherapy can help shrink a secondary cancer in the brain and improve symptoms. Your doctors might suggest using a radiotherapy technique called stereotactic radiotherapy (SRT). This technique targets the tumour in the brain while sparing the normal brain tissues. SRT is not suitable for everyone with a brain tumour.

Someone having radiotherapy



Your doctor will discuss your treatment plan and the possible side effects with you.

Radiotherapy does not make you radioactive. It is perfectly safe for you to be with other people, including children, after your treatment.

Side effects

Radiotherapy will make you feel tired. This can last for some weeks after your treatment finishes. Other side effects will depend on the part of your body being treated and how much radiotherapy you are having. The side effects are usually milder with radiotherapy that is given to improve symptoms. This is especially true if you are only having one or two treatments.

Our booklet **Understanding radiotherapy** explains more about the side effects of radiotherapy. We also have more information about radiotherapy for secondary bone cancer in our booklet **Understanding secondary cancer in the bone**. You can order our booklets by calling us on **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Surgery

Surgery is mainly used to help control the growth of advanced melanoma and relieve symptoms, but usually only when it has not spread very much. It can be used to treat melanoma that has spread to:

- areas of skin distant from the original melanoma
- lymph nodes distant from the original melanoma
- the brain
- the liver (but only if the cancer has spread to a single place in the liver)
- the lungs (but only if the cancer has spread to a single place in the lungs).

Surgery can sometimes be used to remove a secondary tumour. This is called a metastasectomy.

Melanoma that has spread to the skin

Surgery can be used to remove a melanoma that has spread to the skin and is causing lumps to appear. Sometimes these lumps may bleed or cause discomfort. Lumps can often be removed with a simple operation. This can be done under a local or general anaesthetic, depending on the amount of skin being removed.

You may have the operation as an outpatient, or you may need to stay in hospital overnight. Occasionally, you may need to have skin taken from somewhere else on the body to replace the skin that is removed (a skin graft). Your surgeon or specialist nurse will explain more about this. We have more information about skin grafts we can send you.

Your stitches will be removed about a week after surgery, unless you have dissolvable stitches. You may need to have your wound cleaned and dressed until it is healed. The hospital nurses can show you how to do this, or they can arrange for a district nurse to do it for you at home.

Melanoma that has spread to the lymph nodes

If melanoma spreads to distant lymph nodes, they may become enlarged or feel hard. If this is uncomfortable or painful, you may have an operation to remove the lymph nodes.

You will have the operation under a general anaesthetic, and you will probably be in hospital for a few days. The type of operation you have will depend on where the lymph nodes are. Your surgeon or specialist nurse will tell you more about what to expect.

After the operation, you may have a small tube (a drain) to remove any fluid that builds up around your wound. The drain is connected to a small suction bottle. The drain will be removed when most of the excess fluid has been drained away, usually within a few days.

The wound will be covered with a dressing and your stitches or staples will be removed 7 to 10 days later, unless they are dissolvable. District nurses can visit you at home and clean and dress your wound, if needed.

After the lymph nodes have been removed, there is a risk that you could develop swelling in an arm or leg, or another part of the body. This is called lymphoedema (see page 58). If this happens, it will be on the same side that the lymph nodes were removed from.

Melanoma that has spread to the brain

If scans show that there is only one secondary tumour in the brain and no other secondary melanomas in the body, it may be possible to remove it with surgery. You will usually be referred to a specialist surgeon (a neurosurgeon) to see whether an operation is possible.

This type of surgery will be done in a specialist centre. Your neurosurgeon and specialist nurse will tell you what to expect before and after your operation. You will probably be in hospital for at least a week.

Steroid drugs are usually given to help reduce any swelling around the tumour and improve your symptoms. You will probably be prescribed these before your operation and for a few weeks afterwards, depending on your symptoms. You may be given radiotherapy after surgery.

Melanoma that has spread to other parts of the body

If the melanoma has spread to a single area of the liver or lungs and there is no melanoma elsewhere in the body, it may be possible to remove the tumour with surgery. However, this is major surgery and it will not cure the melanoma. Your specialist will discuss the risks and possible benefits of the operation with you. You will usually be referred to a specialist surgeon who will assess you to find out whether an operation is suitable for you.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy can help to control or slow the growth of some melanomas for a time. Your cancer specialist will explain more about the possible benefits and side effects.

There are several chemotherapy drugs that may be used to treat advanced melanoma. The most commonly used drug is called dacarbazine (DTIC). It can be used alone or occasionally in combination with other drugs.

How chemotherapy is given

You usually have chemotherapy drugs as an injection into a vein (intravenously), or sometimes by mouth (orally). You may be given a single drug or a combination of drugs.

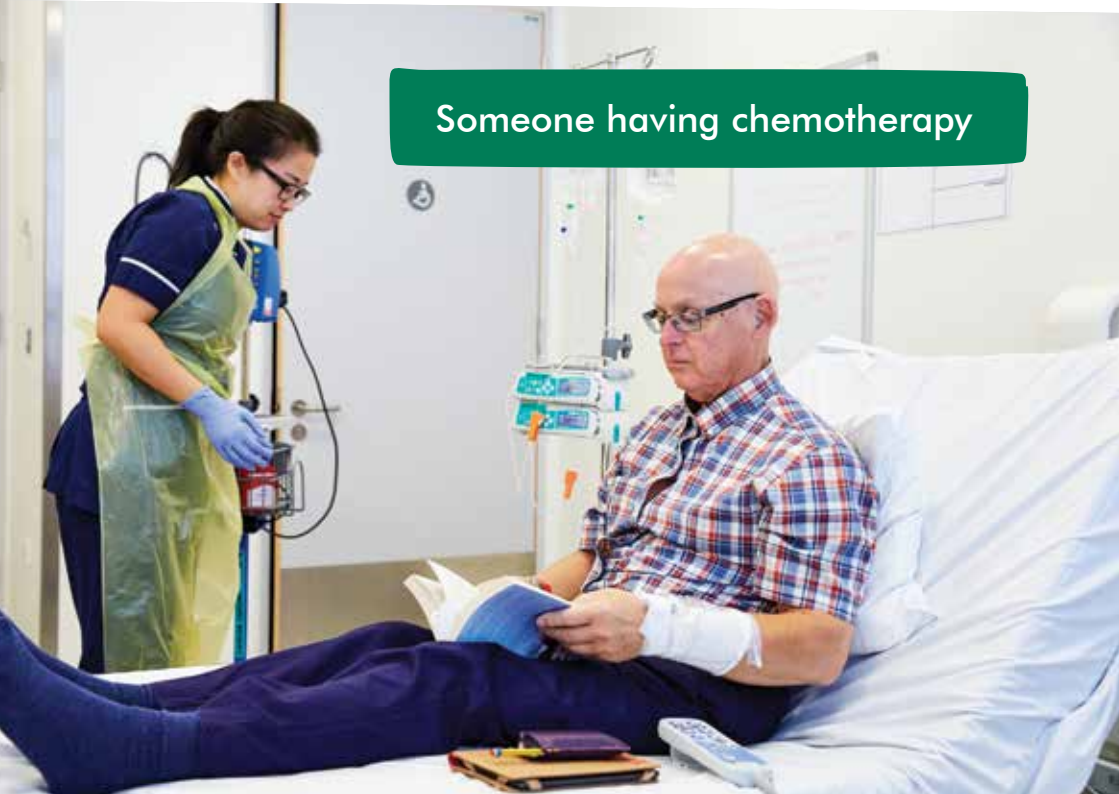
You will normally have chemotherapy as an outpatient, which means you can go home on the same day. Occasionally you may have it during a short stay in hospital.

Side effects

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that is planned for you.

We have more information on chemotherapy and individual chemotherapy drugs on our website ([macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)). You may also find our booklet **Understanding chemotherapy** helpful.

Someone having chemotherapy



Other treatments

Surgery and radiotherapy may be useful treatments for melanoma if it has not spread too far. But if you have a lot of skin nodules, it may be difficult to remove them all with surgery or treat them all with radiotherapy. In this situation, your specialist may advise some other treatments to help shrink the nodules or to relieve symptoms such as pain or bleeding. These treatments are usually carried out in specialist centres.

Laser therapy

This is when a high-intensity beam of light is directed at the affected areas of your skin to destroy the melanoma cells. You can have this treatment as an outpatient.

Chemotherapy into a limb (regional chemotherapy)

You may have chemotherapy directly into an arm or leg. This can treat clusters of melanomas that have come back on the same limb. These are called satellite lesions or in-transit metastases. The treatment is only done if the melanoma has not spread anywhere else in the body.

There are two ways of giving chemotherapy into a limb. These treatments are only carried out in specialist centres in the UK.

Isolated limb perfusion (ILP)

This is a way of giving high doses of chemotherapy directly into a limb. The limb is isolated using a tight band (tourniquet). This means the drugs do not go to other areas of your body. So you are unlikely to get the side effects chemotherapy usually causes when it circulates around the body.

During the procedure, the blood flow from your limb is temporarily disconnected from the rest of your body. The blood from your limb is circulated through a pump and back into your limb. The chemotherapy drugs are given into the blood and circulate through your limb for up to 90 minutes. The drugs are then flushed out of the limb using salt water (saline). The procedure is done under a general anaesthetic and usually involves staying in hospital for three to seven days.

The main side effects of this treatment are swelling, redness and occasionally blistering of the skin on the affected limb. These side effects usually get better after six to eight weeks, but in some people they may last longer. Tell your doctor or nurse about any side effects or problems you are having. There is usually something they can do to make things easier.

Isolated limb infusion (ILI)

This is like isolated limb perfusion, but the blood from the limb does not go through a pump. This makes it a simpler and quicker procedure to do than isolated limb perfusion.

Your doctors can tell you more about isolated limb infusion if this is a suitable treatment for you.

We have more information about regional chemotherapy on our website.

Electrochemotherapy

Electrochemotherapy is a new treatment. It is used to treat cancers affecting the skin and can help to control symptoms when other treatments are no longer working.

Electrochemotherapy is a combination of chemotherapy and a small electrical current. A low dose of chemotherapy is injected into the tumour or into a vein (intravenously). An electrical pulse is then given directly to the cancer cells using an electrode. The electrical pulse helps the chemotherapy get into the cancer cells. Once inside the cancer cells, the chemotherapy destroys them.

If you are having an injection into a tumour, a local anaesthetic will be used to numb the area first. Sometimes you will have a general anaesthetic if lots of tumours are being treated at the same time. Treatment takes between 10 and 60 minutes. You usually have it as an outpatient but it may involve an overnight stay in hospital. The treatment can sometimes be repeated.

Because electrochemotherapy is a new treatment and still experimental, it is not yet widely available. Your doctor or specialist nurse will be able to give you more information about this treatment if it is suitable for you.

Side effects of electrochemotherapy

The side effects are usually mild.

Some people get pain in the area where the electrode touches their skin. This can last for a few days. Tell your doctor or specialist nurse if you have any pain. They can give you painkillers.

During the treatment, you may get muscle contractions that can be uncomfortable. Tell your doctor if this happens. Slightly changing the way the treatment is given can help. The contractions will stop after the treatment is finished.

Other side effects include redness and swelling in the treated area, a rash and scarring. The chemotherapy may cause mild sickness (nausea).



Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Current research

There may be trials looking at new drugs or different chemotherapy drugs to treat advanced melanoma. Some of these trials may test different combinations of drugs to see whether the combination is more effective than one drug given alone.

Most trials have very specific entry criteria. It is only possible to take part in the trial if you fit the criteria. For example, you may need to have tried certain treatments first. Or the melanoma cells may need to have certain characteristics for a specific trial drug to be used. Your doctor will let you know about any trials that may be suitable for you.

Our website has information about current clinical trial databases. Visit [macmillan.org.uk/clinicaltrials](https://www.macmillan.org.uk/clinicaltrials)

Follow-up

After your treatment, you will be seen regularly by your cancer specialist and possibly a specialist nurse at the hospital. They will monitor any potential side effects caused by the treatment, how you have responded to your treatment and how any symptoms have improved. You may have further scans, x-rays or blood tests. They will show you how to examine your skin yourself for any changes.

Many people find that they get anxious before appointments. This is natural and it may help to get support during this time from family, friends, or one of the organisations listed on pages 89–93. If you have any problems, or notice any new symptoms in between your regular check-ups, tell your doctor as soon as possible.



LIVING WITH ADVANCED MELANOMA

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Coping with symptoms and side effects

Your doctors and nurses will regularly check whether you are having any symptoms or side effects. It is important to tell your medical team how you are so they can arrange appropriate help and treatment.

For some people, treatment may no longer be controlling the cancer. In this situation, your doctor may suggest that the aim of treatment changes from trying to shrink the cancer to reducing troublesome or distressing symptoms. This will help you feel better and have the best possible quality of life.

Palliative care teams based in hospitals and the community are experts in helping to control symptoms such as pain. Your GP or cancer specialist can refer you to a palliative care team.

In this section, we describe some common symptoms that people with advanced melanoma experience and some ways of relieving them.

We have more detailed information in our booklet **Managing the symptoms of cancer**. To order it, visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

Tiredness (fatigue)

You may get tired more easily and your body may no longer feel as strong. This could be because of the cancer or because of the side effects of treatment.

If you have fatigue, planning ahead is important. Plan your day so that you have time to do the things you want to do most. You may find some of these suggestions help you deal with everyday tasks:

- Spread housekeeping tasks over the week and ask for help if you can.
- Try shopping online so it is delivered to your home, or ask a relative or friend to do your shopping for you.
- Cook simple meals and eat small meals and snacks throughout the day.
- Have a bath instead of a shower and try to wear clothes that are easy to take off.
- If you have children, explain that you are feeling tired. Plan activities where you can sit down while spending time with them.
- Avoid driving when you feel tired. Family or friends may be able to drive you instead.

Practical aids, such as walking sticks, walking frames or wheelchairs, can also be useful. They may help you move around more than you could on your own.

We have more suggestions on how you can deal with cancer-related tiredness at [macmillan.org.uk/fatigue](https://www.macmillan.org.uk/fatigue)

Eating changes

You may notice a change in your eating habits. This may be a loss of appetite or changes in the way you smell and taste food. The cancer and its treatment can cause problems, such as difficulty swallowing or feeling sick. Even if you are still eating well, you may lose weight and muscle because the cancer can change the way your body uses the energy in your food.

If you are worried about weight loss or changes in your eating habits, talk to your doctor or nurse. You can also ask to see a dietitian, who can help you find ways to eat well.

These tips may help if you are struggling to eat:

- Try having frequent snacks or small meals. These can be more manageable than three large meals a day.
- Choose foods that you enjoy and ignore those that do not appeal to you. You can try them again after a few weeks if your appetite improves or your sense of taste returns.
- If you can only manage small amounts, choose foods or drinks that will give you energy and protein so you get the most out of what you eat.
- If you don't feel like eating, try a nourishing drink. You can make a smoothie by blending or liquidising soft fruits (fresh or frozen) with fortified milk, fruit juice, and ice cream or yoghurt. Your doctor, nurse or dietitian can also prescribe or recommend supplement drinks and puddings for you.
- If you feel you need more help at home with cooking or eating, tell your GP or contact the dietitian at your hospital. They may be able to arrange meals on wheels or a home help for you.

We have more information about eating problems and how to cope with them.

Feeling sick or being sick

Some treatments for advanced melanoma cause sickness (nausea). Sometimes the melanoma itself may cause you to feel sick. This can often be relieved by anti-sickness tablets (anti-emetics). There are different types of anti-emetic available. Your doctor will find the one that suits you best. Steroids are often used. These can help to relieve sickness and make you feel more energetic, as well as improve your appetite.

We have information about controlling nausea and vomiting.

Pain

Pain is often caused by the cancer itself, but not everyone with cancer gets pain. If you have pain, there are many different types of painkiller that your doctor can prescribe to control it. Some are better for certain types of pain. Your doctor or specialist nurse will be able to advise you on the best painkillers for you.

Usually, your doctor will prescribe painkillers to take at set times of the day on a regular basis, rather than as and when you need them. Taking painkillers regularly prevents pain building up and keeps it better controlled.

Many painkillers can cause constipation, so it is important to eat foods high in fibre and to drink plenty of fluids. Your doctor can prescribe a laxative with your painkillers to prevent constipation.

Radiotherapy can also be used to relieve pain (see pages 36–38).

We can send you more detailed information about painkillers and other ways of managing pain.

Coping with a change in appearance

Some people may have had a melanoma on a visible part of the body, such as the face or neck, and its removal may change their appearance. Others may have some scarring from the surgery. Changes in appearance can be difficult to come to terms with. Some skin clinics have a make-up specialist who can advise on the best way to cover up scars. There are also organisations that provide camouflage make-up to cover scars (see page 89).

Coping with a change in how you look can be difficult. It is important to get support. You may find it helps to talk things through with your hospital team, someone close to you or a trained counsellor. The organisations listed at the end of this booklet can help.

You may also find it helpful to read our booklet **Body image and cancer**.

Lymphoedema

If the melanoma has spread to the lymph nodes in the groin or under the arm, you may develop swelling of a leg, arm or other part of your body. The lymph nodes help to drain a fluid called lymph. Lymph travels along fine tubes (lymphatic vessels) that connect the lymph nodes. The melanoma cells can block the flow of lymph. If this happens, fluid will collect in the tissues under your skin, making your leg or arm swell. This is called lymphoedema.

We have more information in our booklets **Understanding lymphoedema** and **Understanding melanoma – lymph node assessment and treatment**. They both explain this condition in more detail.

Effects on your sex life

Some people find that the cancer has no effect on their sex life. Others find that the melanoma or its treatment have physical effects that make them feel less interested in sex or feel self-conscious about it. You can talk to your team about any worries you have.

We have more detailed information about sexuality and cancer for men and women. To order our booklets, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.



Complementary therapies

Some people find that complementary therapies help them feel stronger and more confident in dealing with advanced cancer. These therapies can usually be used alongside conventional treatments and medicines.

Complementary therapies can help to improve your quality of life and well-being, and can sometimes help to reduce symptoms. Some complementary therapies, such as meditation or visualisation, can be done by the person with cancer themselves and can reduce anxiety. Other therapies, such as gentle massage, can be done by relatives or carers and can help them to support you.



Physical contact and touch can be among the most powerful forms of support for people who are faced with uncertainty, fear or pain, whether emotional or physical. Many hospices and hospitals offer complementary therapies alongside conventional care. These may include:

- aromatherapy
- massage
- relaxation, visualisation or guided imagery techniques
- acupuncture.

Always let your cancer specialist know if you are taking any supplements or other medicines. Some of these may interact with chemotherapy or targeted therapy.

We can send you more information about cancer and complementary therapies.

'Counselling, yoga, medication, meditation, massage, exercise – I've used them all at different times and they all have their place as far as I am concerned. I do think exercise and making sure I am well hydrated are as important as anything.'

Anne

If you live alone

Living alone can add extra stresses. Even though you may value your independence, being ill can make you feel very lonely and frightened.

It is all right to ask for help. People who care about you will want to help in any way they can. Some people may find it difficult to talk, but may be happy to help in more practical ways, such as doing your shopping or helping with your garden. You could make a list of practical things that would make your life easier. If people offer to help but are not sure what to do, they can then choose to do something from your list.

Other people may be able to talk with you and listen to you and share your worries and fears.

Marie Curie has a free helper service available in parts of the UK. Someone can visit you to have a chat over a cup of tea, help you get to an appointment, run an errand, or just be there to listen when you need a friendly ear. For more information, visit [mariecurie.org.uk/helper](https://www.mariecurie.org.uk/helper) or call **0800 090 2309**.

Your GP, social worker, or district or community nurse will also be able to tell you what help and support is available from health, social care and voluntary organisations (see next page).

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The **hospital social worker** can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as **Macmillan nurses**. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our **cancer support specialists** on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.



YOUR FEELINGS AND RELATIONSHIPS

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Coping with feelings

It is natural to have a mix of emotions when coping with advanced cancer, such as fear or anger. These feelings can occur at different times, and they may vary in strength and frequency. However, people often find that over time their feelings become easier to cope with.

Uncertainty

Coping with advanced cancer can mean living with doubt and uncertainty. You may be concerned about practical matters such as your work or finances. You may be worried about your treatment, pain or other symptoms, or about losing your independence or mobility. You may be anxious about the cancer's effect on those you love and how you will all cope as it develops. These are all common thoughts people have.

Uncertainty is one of the hardest things to deal with for you and your family and friends, especially when you are trying to live life as normally as possible. It can cause a lot of tension. You may feel irritable, angry and frightened. It is difficult to make plans when you don't know what is ahead. Even if you ask your doctors what is likely to happen, you may find their answers are vague because they cannot say for sure.

However, many people find they can learn to live with uncertainty. One thing that can help is to take control of the things they can do something about.

Fear

Many people with advanced cancer feel frightened. You may have times when you feel afraid of the illness itself, the symptoms, or the treatment and its possible side effects. You may worry about the effect it will have on your family. People often worry about the future or about dying.

Anger

It is natural to feel angry if you have advanced melanoma. You may feel angry about feeling unwell, going through treatment and having to cope with the side effects. You might also be angry about the impact the cancer has had on your life. It may have affected your ability to work or your relationships. You may feel frustrated that your plans will be disrupted by tests and treatment, and that your long-term plans have suddenly become uncertain. Living with the uncertainty that comes with advanced cancer is likely to be physically and emotionally demanding.

'I think I hit just about every emotion at least four or five times an hour after I was first diagnosed. It settled down slowly as I made a bit more sense of what was happening and what I needed to do. Counselling can be a great help.'

Gragon

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have advanced cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

'When my condition became serious, I was struck by disbelief. I thought "it can't be me" and that there had been a mistake. That was my first reaction; then I started to think that it was just bad luck.'

Philip

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our online community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

Talking about feelings

We all express our feelings in different ways. It is often clear how someone is feeling by their behaviour, what they say and how they say it. But sometimes, one emotion can disguise another. For example, a person might be frightened but express their fear by being short-tempered and irritable, or angry with those around them. Talking about our feelings can help us understand our behaviour and what is behind it. This is not always easy.

If you can, find someone you can talk to about how you feel, such as a family member or friend. Some people prefer to talk to someone outside their immediate circle of family and friends. Your GP, palliative care nurse or doctors and nurses at the hospital will usually ask how you are. This will give you the opportunity to talk about your feelings and emotions if you want to. You might find this easy if you already know them and feel comfortable with them.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

Talking to children and grandchildren

It can be very difficult to talk to your children or grandchildren about cancer. It is probably best to be honest with them and tell them your cancer has come back or spread. Even very young children will sense when something is seriously wrong. However much you want to protect them, if you pretend everything is fine, they may feel they have to keep their worries to themselves. Their fears may be worse than the reality.

How and what you tell them will depend on their age and how much they can understand. It may be a good idea to choose to tell them at a time when you and your partner, relatives or close friends can all be together. Then the children will know there are other adults they can share their feelings with and who will support them.

Children of any age may worry that you are going to die. If your cancer is likely to be controlled for a long time, it is important to tell them this. If the cancer is more advanced, it is helpful to sensitively prepare them for your death. Obviously this can be a very difficult thing to do, and you may need help and support. We have a booklet called **Preparing a child for loss** that may help.

'I speak honestly with my partner and my children about the future and then they can talk to me honestly too.'

Deborah

Teenagers

Teenagers may find it particularly difficult, because they are going through a lot of emotional changes themselves. You may need them to take on more responsibilities around the home at a time when they are looking for more independence. If they are finding it hard to talk to you, encourage them to talk to someone close who can support them, such as a relative or family friend. They may also find it useful to look at the website riprap.org.uk, which is for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers when an adult has cancer** has more information. There is also a video on our website that may help at macmillan.org.uk/talkingtochildren



What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.





FINANCIAL SUPPORT AND WORK

Financial help and benefits

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Work

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Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled. There are two different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don't qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called **Universal Credit**. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least three months and expect them to last for at least nine months. PIP replaces an older benefit called **Disability Living Allowance (DLA)** for adults.

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least six months.

If you are terminally ill, and may be expected to live for less than six months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than six months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for **Carer's Credit**. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Scotland and Wales) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 92).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 92–93.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, or whether to go back at all. This will depend mainly on the type of work you do and how much your income is affected. It is important to do what is right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job-share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It is important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. This means their employer must not discriminate against them for any reason. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information. There is also lots more information at macmillan.org.uk/work



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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation). There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

If you'd like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk. You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://www.macmillan.org.uk/talktous)**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online community

Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)



Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Melanoma support organisations

The British Association of Skin Camouflage

Tel 01254 703 107

(Mon–Fri, 10am–4pm)

www.skin-camouflage.net

Shows people how to use make-up as skin camouflage.

Changing Faces

Tel 0300 0120 275

(Mon–Fri, 10am–4pm)

Email

info@changingfaces.org.uk

www.changingfaces.org.uk

Offers support and information to people who have any sort of disfigurement, and their family and friends. Has skin camouflage practitioners in locations across the UK.

To find your local centre, visit **changingfaces.org.uk/skin-camouflage/clinic-venues**

Lymphoedema Support Network

Tel 020 7351 4480

Email admin@lsn.org.uk

www.lymphoedema.org

Provides practical help, information and support. Runs a helpline and produces a range of fact sheets. The website lists local lymphoedema support groups throughout the UK.

Skin Cancer Research Fund (SCaRF)

Tel 01174 148 755

www.skin-cancer-research-fund.org.uk

Promotes research into the causes, prevention and treatment of skin cancer.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus

Northern Ireland

Helpline 0800 783 3339

(Mon–Fri, 9am–1pm)

Email

helpline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531

(Mon–Fri, 9am–5pm)

Email

info@cancersupportscotland.org

www.

cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Tenovus**Helpline** 0808 808 1010

(Daily, 8am–8pm)

Email

info@tenovuscancercare.org.uk

www.**tenovuscancercare.org.uk**

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

Cancer registries**The cancer registry**

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration Service**Tel** 020 7654 8000**Email** enquiries@phe.gov.uk**www.ncr.nhs.uk****Scottish Cancer Registry****Tel** 0131 275 7777**Email** nss.csd@nhs.net**www.isdscotland.org/****Health-Topics/Cancer/****Scottish-Cancer-Registry****Welsh Cancer****Intelligence and****Surveillance Unit (WCISU)****Tel** 02920 373500**Email**

general.enquiries@wales.nhs.uk

www.wcisuwales.nhs.uk**Northern Ireland****Cancer Registry****Tel** 028 9097 6028**Email** nicr@qub.ac.uk**www.qub.ac.uk/nicr****Counselling and emotional support****British Association****for Counselling and Psychotherapy (BACP)****Tel** 01455 883 300**Email** bacp@bacp.co.uk**www.bacp.co.uk**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

**UK Council for
Psychotherapy (UKCP)**
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial and legal advice

**Benefit Enquiry Line
Northern Ireland**
Helpline 0800 220 674
(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)
Textphone
028 9031 1092

**[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice
Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England
www.citizensadvice.org.uk

Wales
**[www.
citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

**Department for Work
and Pensions (DWP)
Personal Independence
Payment (PIP) Helpline**
0345 850 3322

Textphone 0345 601 6677
(Mon–Fri, 8am–6pm)

Carer's Allowance Unit
Tel 0345 608 4321

Textphone 0345 604 5312
(Mon–Thurs, 8.30am–5pm,
Fri, 8.30am–4.30pm)

**[www.
gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

**Personal Finance Society –
‘Find an Adviser’ service**
**[www.thepfs.org/yourmoney/
find-an-adviser](http://www.thepfs.org/yourmoney/find-an-adviser)**

Use the website to find qualified financial advisers in your area of the UK.

Unbiased.co.uk
Helpline 0800 023 6868
Email contact@unbiased.co.uk
www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for carers

Carers Trust
Email support@carers.org
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK
Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon–Fri, 10am–4pm)
Helpline (Northern Ireland)
028 9043 9843

Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

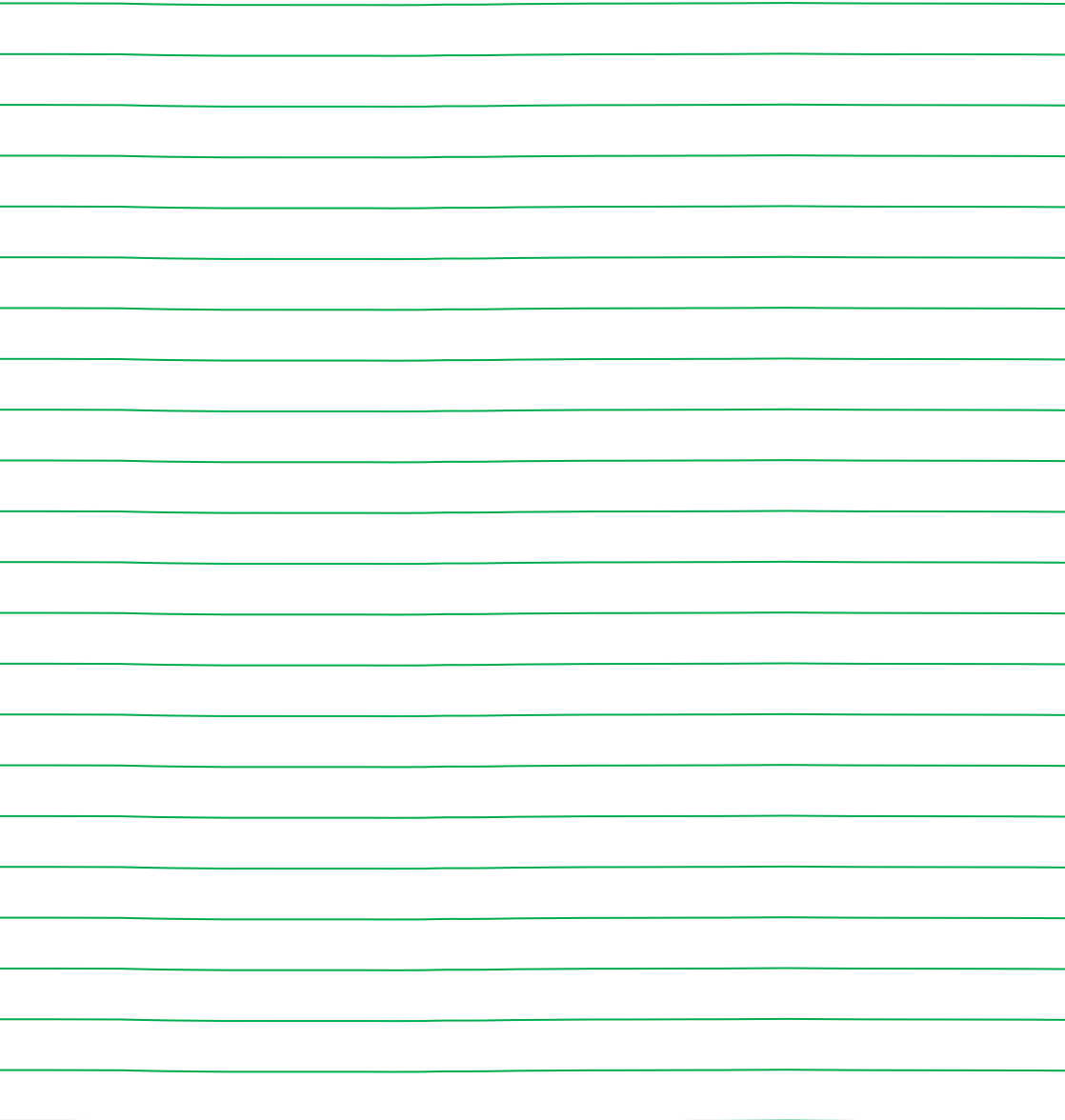
**Advanced cancer and
end-of-life care**

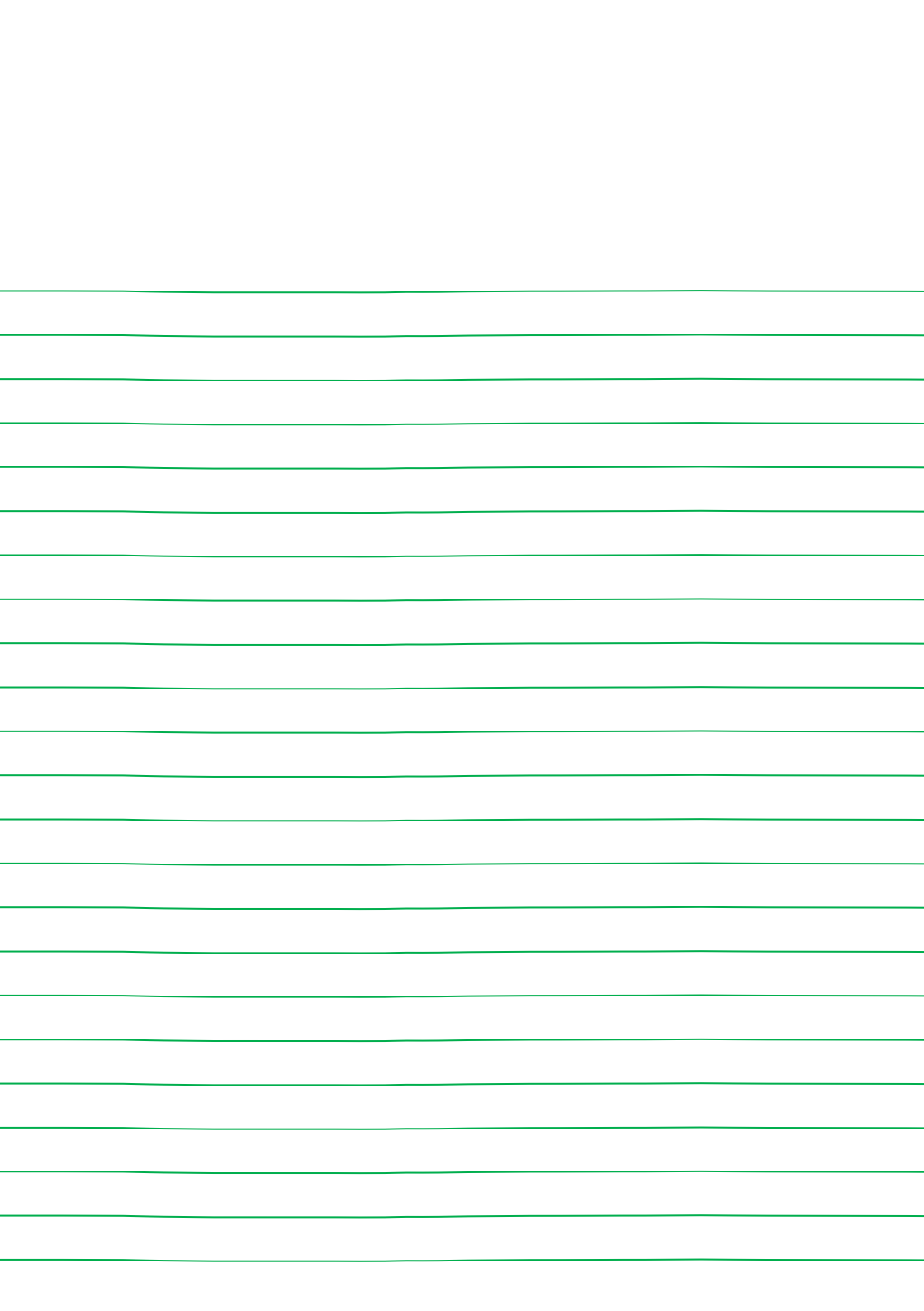
Marie Curie
Helpline 0800 090 2309
(Mon–Fri, 8am–6pm,
Sat, 11am–5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions.





Disclaimer

We make every effort to ensure that the information we provide is accurate and up-to-date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr James Larkin, Consultant Medical Oncologist; and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Valerie Doherty, Consultant Dermatologist; Ann Irwin, Clinical Nurse Specialist – Skin Cancer; Dr Sarah Westwell, Consultant Clinical Oncologist; and Silvana Zanoto-Garemmog, Macmillan Skin Clinical Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

Sources

We've listed a sample of the sources used in this publication below. If you would like further information about the sources we use, please contact us at [**bookletfeedback@macmillan.org.uk**](mailto:bookletfeedback@macmillan.org.uk)

Dummer et al. Cutaneous melanoma. ESMO clinical practice guidelines for diagnosis, treatment and follow up. *Annals of Oncology*. 2015. 26 Suppl 5.

Marsden et al. Revised UK guidelines for the management of cutaneous melanoma. *British Journal of Dermatology*. 2010. 163.

Melanoma NCCN evidence blocks, version 2. 2016. National Comprehensive Cancer Network (NCCN) clinical practice guidelines in oncology.

National Institute for Health and Care Excellence (NICE). www.nice.org.uk (accessed February 2017).

Ribas et al. Cutaneous melanoma. In: Devita, Hellman and Rosenberg. *Cancer: principles and practice of oncology*. 10th edition. Philadelphia, PA: Lippincott Williams & Wilkins. 2015.

Sosman. Overview of the management of advanced cutaneous melanoma. UpToDate. 2015. Available from: www.uptodate.com/contents/overview-of-the-management-of-advanced-cutaneous-melanoma (accessed February 2017).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money

Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Security number

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Signature _____

Date / / _____

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about advanced melanoma. It is for anyone who has been diagnosed with advanced melanoma. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of advanced melanoma, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call our support line.

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What's this logo? Visit **macmillan.org.uk/ourinformation**

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MACMILLAN.
CANCER SUPPORT**