# Understanding advanced melanoma

> "No individual journey is ever the same. However, I have found that it can be somewhat possible to live like a typical 20-something. I hope there are other people like me doing the same."

Jolene, diagnosed with advanced melanoma

# About this booklet

This booklet is about a type of skin cancer called melanoma. It is for anyone who has melanoma that has spread to another area of the body. This is called advanced or metastatic melanoma. There is also information for carers, family members and friends.

The booklet explains advanced melanoma. It gives information about how melanoma is diagnosed and treatment options. It also has information about feelings, practical issues and money.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

This booklet does not have information about early melanoma, or other types of skin cancer. The following booklets may help:

- **Understanding melanoma: surgery to remove a melanoma**
- **Understanding melanoma: tests and treatment after surgery to remove a melanoma**
- **Understanding skin cancer**

More information about these booklets can be found on page 82.

# How to use this booklet

This booklet is split into sections to help you find what you need. You do not 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. On pages 88 to 99, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (page 100).

# Quotes

In this booklet, we have included quotes from people who have had advanced melanoma which you may find helpful. These are from people who have chosen to share their story with us. This includes Jolene, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

# 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**, 7 days a week, 8am 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**.

# Contents

# Advanced melanoma

# What is advanced melanoma?

Melanoma is a cancer that usually starts in the skin. It usually starts as a new mole or in a mole you already have.

Advanced melanoma is when melanoma cells spread from where they started (the primary melanoma) to other parts of the body. It is also called metastatic melanoma.

Melanoma cells can travel through the blood or the lymphatic system. The lymphatic system helps to protect us from infection and disease. It is made up of fine tubes called lymphatic vessels that connect to groups of small lymph nodes (glands) throughout the body.

When the melanoma cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary melanoma or a metastasis. The secondary cancer is made up of melanoma cells. Doctors treat secondary melanoma as melanoma, no matter where it is in the body. For example, they treat a secondary melanoma tumour in the lung as melanoma, not as lung cancer.

Sometimes melanoma has already spread to another part of the body when it is first diagnosed. Less commonly, some people are diagnosed with advanced melanoma without ever finding the primary melanoma.

Advanced melanoma is usually stage 4 melanoma. The stage of a cancer describes its size and if it has spread. Stage 4 means the melanoma has spread to other areas of the body such as:

- other areas of the skin
- the lungs, liver, bones or brain.

Some stage 3 melanomas that cannot be removed with surgery may be described and treated as advanced melanoma. You can read more about melanoma staging on our website or in our booklet **Understanding melanoma: tests and treatment after surgery to remove a melanoma** (page 82).

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

# Signs and symptoms of advanced melanoma

Advanced melanoma can cause different symptoms. This depends on where in the body melanoma has spread to. We describe them over the next few pages.

Some people may also have some general symptoms.

Many of the following symptoms can be caused by less serious conditions. But if you have any of these, speak to your cancer doctor, specialist nurse or GP straight away.

## Distant lymph nodes

Melanoma may spread to lymph nodes far away from where the melanoma started. This is different to melanoma that has spread to lymph nodes nearby.

You may notice a lump, and the lymph nodes may feel hard and swollen. Sometimes, they press on tissues or nerves nearby, causing pain.

## Skin

Melanoma that spreads to areas of skin far away from the original melanoma appears as firm or hard lumps called nodules. Or there may be flat, grey or purple areas of skin. These lumps or areas may bleed.

## Lungs

If melanoma spreads to the lungs, it may cause symptoms such as:

- breathlessness
- a cough
- coughing up blood.

We have more information about the symptoms of secondary lung cancer. Visit **macmillan.org.uk/secondary-lung-cancer**

## Brain

Melanoma that has spread to the brain may cause headaches and sickness. These can be worse first thing in the morning. Other symptoms depend on the area of the brain affected. They may include numbness or weakness in a limb, or having a seizure (fit).

We have more information about the symptoms of secondary brain cancer. Visit **macmillan.org.uk/secondary-brain-cancer**

## Liver

Melanoma that has spread to the liver can cause:

- discomfort or pain in the liver area – the right side of the tummy, under the ribs
- sickness.

We have more information about the symptoms of secondary liver cancer. Visit **macmillan.org.uk/secondary-liver-cancer**

# Bones

If melanoma spreads to the bones, it can cause pain in the bone. We have more information about the symptoms of secondary bone cancer in our booklet **Understanding secondary bone cancer** (page 82).

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). If you have symptoms of spinal cord compression, contact your doctor immediately as you may need urgent surgery or radiotherapy. Symptoms include:

- back or neck pain, which might feel like a band around your chest or tummy
- muscle weakness
- numbness and weakness in the legs
- problems controlling your bladder or bowels.

We have more information in our **MSCC alert kit** (page 82).

We have more information about MSCC on our website. Visit **macmillan.org.uk/malignant-spinal-cord-compression**

## Digestive system

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

- pain in the tummy (abdomen)
- constipation or diarrhoea for no obvious reason
- sickness (vomiting)
- vomiting up blood
- blood in your poo (stools).

## General symptoms

The general symptoms of advanced melanoma include:

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

You can talk to one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

# Diagnosing advanced melanoma

# How advanced melanoma is diagnosed

If you have already had treatment for melanoma, you may have check-ups at a clinic. Sometimes advanced melanoma is diagnosed through tests you have at the clinic. Or your cancer doctor may arrange tests to find out what is causing your symptoms.

If you notice new symptoms between check-ups, contact your cancer doctor or specialist nurse. They may arrange some tests for you. Do not wait until your next appointment.

Sometimes melanoma has already spread to another part of the body when it is first diagnosed. Or tests after the melanoma has been removed may show it has spread.

A small number of people not previously diagnosed with melanoma are diagnosed with advanced melanoma. In this situation, doctors look for the primary melanoma and arrange any tests you may need. Occasionally, they cannot find the primary melanoma. This is called melanoma of unknown primary. Doctors are not certain why this happens. It may be because the person's immune system helped shrink the primary melanoma. Or the primary melanoma may have been removed for another reason.

If you are diagnosed with advanced melanoma, you will probably have difficult feelings to cope with. These may become easier to manage with time, and as you start making treatment decisions and plans (page 31). We have help and support available. Visit **macmillan.org.uk/emotions**

You can talk to one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

> "I was diagnosed with stage 1 melanoma via a mole on my neck, and was diagnosed with stage 4 melanoma after having had a lump removed from my arm. Following MRI and CT scans, I was diagnosed with both a lung tumour and brain tumour. „
>
> Jolene

# Tests for advanced melanoma

The tests you have depend on your situation. If you are newly diagnosed with melanoma, you may start with tests on the nearby lymph nodes. We have more information in our booklet **Understanding melanoma: tests and treatment after surgery to remove a melanoma** (page 82).

If the melanoma has spread to the lymph nodes, you may have further tests. Tests will check whether melanoma has spread to other parts of the body. They may include:

## Blood tests

You may have a blood test to check your general health and how well your bone marrow, kidneys and liver are working. Bone marrow is where blood cells are made.

## CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website. Visit **macmillan.org.uk/ct-scan**

Having a CT scan

# MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit **macmillan.org.uk/mri-scan**

.

# Ultrasound scan

An ultrasound scan uses sound waves to build up a picture of internal organs.

The person doing the scan uses a small device called an ultrasound probe. They move the probe over the skin on the part of the body being scanned. It produces sound waves. These bounce off different parts of the body and make echoes. A computer converts the echoes into a picture.

# Bone scan

A bone scan shows abnormal areas of bone. You have a small amount of a radioactive substance injected into a vein.

## Having a bone scan

The person who does the scan is called a radiographer. They inject a small amount of a radioactive substance through a thin tube (cannula) into a vein in your hand or arm. This is called a tracer. Because it is a small amount, the radiation does not cause you any harm.

You need to wait for 2 to 3 hours between having the injection and having the scan. You may want to take something with you to help pass the time.

Areas of abnormal bone absorb more radiation than normal bone. This means the abnormal bone shows up more clearly on the scanner. The abnormal areas are sometimes called hot spots.

It is not always clear whether hot spots are caused by cancer or by other conditions, such as arthritis. Sometimes doctors also use a CT scan (pages 16 to 17) or MRI scan to help them decide (page 18).

# PET scan

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, contact the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make you feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET and PET-CT scans on our website. Visit **macmillan.org.uk/pet-ct-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 to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Your specialist nurse or a support organisation can also provide support (pages 88 to 99). Or you can talk to one of our cancer support specialists on **0808 808 00 00** 7 days a week, 8am to 8pm.

# Tests on the melanoma cells

About half of all people with melanoma (50%) have a change in the melanoma cells called a BRAF V600e gene mutation. This causes the melanoma cells to make a protein that encourages the cells to grow.

Your cancer doctor will arrange tests to look for this gene change. Tests can be done on melanoma cells that were removed during surgery. Or, sometimes, your doctor might want to take another sample of tissue to test. Your doctor or specialist nurse can explain more about testing for gene changes.

The results tell your cancer doctor if certain targeted and immunotherapy drugs will work for you.

If tests show you have a BRAF gene mutation in the melanoma cells, your doctor may offer you a combination of targeted therapies. This treatment helps to shrink or slow the growth of the melanoma. If you do not have the BRAF gene mutation, you may be offered immunotherapy treatment.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically.

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.

If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 99).

# Treating advanced melanoma

# Treatment overview

The aim of treatment for advanced melanoma is to control the cancer and help you live for longer. Many people are now living for a longer time with advanced melanoma. Your cancer doctor and specialist nurse will explain the different treatment options and their side effects. Your treatment plan may depend on:

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

You and your doctor can then decide on the best treatment for you. Depending on your situation, you may have one or more types of treatment. Sometimes you may have treatment for advanced melanoma as part of a clinical trial. We have more information about clinical trials, visit **macmillan.org.uk/clinical-trials**

These are the main treatments for advanced melanoma:

- Immunotherapy and targeted therapy are the most effective treatments for advanced melanoma (pages 34 to 39). They sometimes cause serious side effects. Your doctor and nurse will explain these so that you know what to look out for. This means side effects can be treated earlier before they become serious.
- Radiotherapy can be used to control symptoms, if the melanoma has spread to the brain, liver, bones or skin (pages 40 to 42).

Other treatments are sometimes used:

- You may have surgery to remove a small number of tumours in 1 area, such as the brain, liver or lungs. These are big operations. Doctors need to make sure the melanoma has not spread anywhere else and that the surgery is suitable for you. Sometimes surgery can be used to remove melanoma that has spread to skin or lymph nodes far from the primary melanoma.
- Chemotherapy is not commonly used but you may have it if other treatments are not suitable for you.

Secondary cancers in the skin may also sometimes be treated with:

- an immunotherapy drug called T-VEC (Imlygic®) – page 50
- chemotherapy into a limb – pages 51 to 52
- electrochemotherapy – page 53
- laser therapy – page 52.

You may also have treatments to control symptoms and side effects alongside treatments such as immunotherapy or targeted therapy. Always tell your doctor or nurse about side effects or symptoms as there are things they can do to help. Controlling these is an important part of your care (pages 66 to 67).

We have more information in our booklet **Coping with advanced cancer** (page 82).

# Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines and the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this. The MDT will usually include the following professionals:

- Oncologist – a cancer doctor who specialises in treating people with cancer using targeted and immunotherapy drugs, radiotherapy and chemotherapy.
- Skin cancer nurse specialist – a nurse who gives information about skin cancer, and support during treatment.
- Dermatologist – a doctor who treats skin problems.
- Plastic surgeon – a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.

Depending on the type of cancer you have, the MDT may also include:

- a physiotherapist
- a dietitian
- an occupational therapist
- a counsellor or psychologist
- doctors and nurses who are experts in symptom control.

After the MDT meeting, your doctor and specialist nurse will talk to you about the best treatment plan for your situation. They will explain the benefits and disadvantages of different treatments.

# Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment, for example to control the cancer and help you live for longer
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

# Decisions about advanced cancer

The aim of your treatment is to control the cancer, help you live for longer and improve symptoms.

This might mean having ongoing treatment with drugs to control the melanoma. The drugs may cause side effects, and you may need help to manage these. But you may also be able to carry on with your everyday life. You can have different treatments depending on when you need them.

Your doctor can often give you an idea of how well a treatment will work. You may decide to have one treatment instead of another because of your own preferences. This might be linked to the side effects of a treatment, or to the amount of time spent at the hospital.

We have more information in our booklet **Making treatment decisions** (page 82).

If it becomes difficult to control the cancer your doctor and specialist nurse will support you. They will make sure your symptoms are managed.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

# Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

# Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**.

# Immunotherapy and targeted therapy drugs

Immunotherapy drugs use the body's immune system to recognise and kill cancer cells. The immune system protects the body against illness and infection.

Targeted therapy drugs target something in or around the cancer cell that is helping it grow and survive.

Immunotherapy drugs called checkpoint inhibitors and targeted therapy drugs are the most effective treatments for advanced melanoma. They can shrink and slow the growth of advanced melanoma. These drugs help you live longer.

Your cancer doctor will explain what drugs are useful for you. They will give you information about how the drug is given and the possible side effects.

Another immunotherapy drug called TVEC (Imlygic®) is sometimes used to treat areas of melanoma in the skin or lymph nodes – page 50.

# Checkpoint inhibitor drugs for melanoma

Checkpoint inhibitor drugs are a type of immunotherapy treatment. They activate white blood cells called lymphocytes to attack cancer cells. Lymphocytes are an important part of your immune system.

Checkpoint inhibitors that are used to treat melanoma include:

- ipilimumab (YERVOY®)
- nivolumab (Opdivo®)
- pembrolizumab (Keytruda®).

You may keep having treatment as long as it is working, and not causing difficult side effects.

You have the drug at a day unit as an outpatient. It is given as a drip into a vein. This is called an intravenous infusion. Sometimes, 2 checkpoint inhibitor drugs are given together. Your cancer doctor or specialist nurse will explain your treatment plan and what to expect.

After the treatment, you have a rest period of a few weeks. Together, the immunotherapy and the rest period are called a cycle of treatment. The length of a cycle depends on the treatment you are having.

We have more information about checkpoint inhibitors on our website. Visit **macmillan.org.uk/treatments-and-drugs**

## Possible side effects

Common side effects of checkpoint inhibitor drugs include:

- feeling tired
- skin changes or rashes
- diarrhoea
- feeling short of breath.

This type of drug affects the immune system and can cause related side effects. Your cancer doctor or specialist nurse will give you information about this. Side effects may be mild, but if they are not treated they can sometimes become serious very quickly. Side effects can start during treatment. They can also start weeks, months, or sometimes more than a year after you finish treatment.

It is important to tell your cancer doctor or specialist nurse about any side effects you have as soon as possible.

Your doctor, nurse or pharmacist will also give you a card with information about your treatment on it. It is important to always have the card with you during treatment and after treatment finishes. You should always show it to any doctor or healthcare professional you need to see or who prescribes you any other medication.

> "My experience of immunotherapy has been positive. I still struggle with fatigue, but the symptoms are less severe than when I had other treatments."

Jolene

# Targeted therapy

Targeted therapy is only used to treat melanoma if tests show that the cancer cells have a change (mutation) in a gene called BRAF. These tests need to be done before you can start this treatment.

You usually have 2 targeted therapy drugs in combination to treat melanoma. Combinations include:

- dabrafenib and trametinib
- encorafenib and binimetinib
- vemurafenib and cobimetinib.

These drugs are also called cancer growth inhibitors. Cancer growth inhibitors block the signals that tell cells in the body to develop and divide. By blocking the signals, these drugs may stop cancer cells from developing or dividing.

## How targeted therapy is given

You take the drugs as tablets or capsules every day. Different drugs are taken in slightly different ways. It is important to follow your cancer team's advice about how to take each drug. You usually keep taking the drugs as long as they are working and not causing difficult side effects.

## Possible side effects

Your cancer doctor or nurse will explain the possible side effects of the drugs you are having. They will give you advice about how these can be managed. Always tell them about any side effects you have so they can help.

Some common side effects include:

- feeling sick
- tiredness
- loss of appetite
- itchy rash or dry, sensitive skin
- sore and red palms of hands and soles of feet
- muscle or joint pain.

We have more information on our website about the side effects of:

- dabrafenib and trametinib
- encorafenib and binimetinib.

To find out more, visit **macmillan.org.uk/treatments-and-drugs**

# Radiotherapy

Radiotherapy is the use of high-energy rays to treat cancer.

For advanced melanoma, radiotherapy may be given to reduce pain and improve other symptoms. This is called palliative radiotherapy.

Radiotherapy can help to improve symptoms when melanoma has spread to different parts of the body.

## Skin or lymph nodes

Radiotherapy may be used to treat melanoma that has spread to skin or lymph nodes far from where the melanoma started. It can be used to help to shrink:

- firm hard lumps on the skin (nodules)
- the size of lymph nodes.

Radiotherapy will also improve symptoms, such as pain, that may be caused by swollen lymph nodes or skin nodules.

## Brain

Radiotherapy can shrink melanoma that has spread to the brain. This can improve symptoms. Your doctors might suggest a radiotherapy technique called stereotactic radiosurgery (SRS). It gives a higher dose of treatment to the tumour without damaging nearby areas of the brain. This is often used instead of radiotherapy to the whole brain. You might have 1 session of SRS, or a few sessions. You may need to have a head frame fitted or wear a specially made mask. This is to make sure the radiotherapy is given as accurately as possible. Your radiographer (person who gives radiotherapy) will explain all this. We have more information about radiotherapy on our website. Visit **macmillan.org.uk/radiotherapy-for-melanoma**

## Bones

Radiotherapy can help reduce bone pain and swelling. It can also be used if melanoma is in the bones of the spine and pressing on the spinal cord. This is called malignant spinal cord compression (page 10). If you have any symptoms of spinal cord compression it is very important to contact your cancer doctor straight away.

You may need only 1 to 5 sessions of radiotherapy to treat your symptoms. Your doctor will talk to you about your treatment plan and possible side effects.

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

We have more information about radiotherapy for secondary bone cancer. Visit **macmillan.org.uk/radiotherapy-secondary-bone-cancer**

# How radiotherapy is given

You have the treatment in the hospital radiotherapy department. You will have a series of short, daily sessions. This is usually every day from Monday to Friday, with a rest at the weekend. Each treatment takes 10 to 15 minutes. Your doctor will talk to you about your treatment plan and the possible side effects. If you are having stereotactic radiosurgery, you may have it as a single high-dose treatment.

Before you start your treatment, it needs to be planned carefully by your team. Your radiographer (person who gives radiotherapy) will explain all this. During treatment you will be alone in the room but you can still talk to the radiographer.

We have more information about how radiotherapy is planned and given in our booklet **Understanding radiotherapy** (page 82).

## Side effects of radiotherapy

After treatment finishes, it may be 1 to 2 weeks before side effects start getting better. After this, most side effects usually go away slowly.

You may have some general side effects, such as feeling tired. This can last for some weeks after your treatment finishes. Other side effects depend on:

- which part of your body is being treated
- the type of radiotherapy you have
- how much radiotherapy you have.

We have more information about radiotherapy side effects. Visit **macmillan.org.uk/side-effects-of-radiotherapy**

# Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is not often used to treat melanoma. Your doctor may recommend having chemotherapy if immunotherapy and targeted therapy are no longer working for you (pages 30 to 35).

Chemotherapy may help control or slow the growth of the melanoma for a time. Your cancer doctor and specialist nurse will explain more about the possible benefits and side effects.

There are different chemotherapy drugs that may be used to treat advanced melanoma. They include:

- dacarbazine (DTIC)
- temozolomide
- carboplatin.

You may have only 1 drug, or a combination. We have more information about chemotherapy drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

## How chemotherapy is given

You usually have chemotherapy drugs as an injection into a vein (intravenously), or sometimes by mouth (orally). Chemotherapy is often given as an outpatient. This means you can go home on the same day.

## Side effects of chemotherapy

Chemotherapy drugs may cause unpleasant side effects. Side effects can usually be well controlled with medicines. They usually go away once treatment has finished. Your cancer doctor and specialist nurse will tell you about the likely side effects and how they can be managed.

We have more information about the side effects of chemotherapy in our booklet **Understanding chemotherapy** (page 82).

## Other ways of giving chemotherapy

Sometimes chemotherapy for melanoma is given in other ways to treat areas of melanoma on the skin. It may sometimes be given into a limb or injected into the tumour along with a small electrical current (electrochemotherapy). You can read more about these treatments on pages 51 to 54.

# Surgery

You do not usually have surgery for advanced melanoma. You may have surgery if:

- there is only 1 tumour
- there are a few tumours, but they are all in 1 area
- the tumours are not too big
- a tumour is causing difficult symptoms.

This may be when the melanoma has spread to:

- areas of skin or lymph nodes far away from where the melanoma started (the primary melanoma)
- the brain
- the liver
- the lungs.

The type of operation you have will depend on where the melanoma has spread to. Your operation will be done by a specialist surgeon. The type of surgeon will depend on the part of the body that is affected.

Surgery to remove secondary melanoma tumours in the brain, liver or lung is a big operation. The surgeon will check to make sure it is suitable for you. They will talk to you about the possible benefits and risks of the surgery before you decide. You usually need scans to check the melanoma has not spread anywhere else (pages 16 to 20). You will also have other tests to make sure you are well enough to cope with the operation.

Before your operation, the surgeon and nurse will talk with you about it. It is important that you understand what it may involve. They will explain what to expect and how to prepare for your surgery.

You may have other treatments before or after your operation.

On the next few pages, we explain how surgery might be used to treat melanoma that has spread to different parts of the body.

## Skin

You may have surgery to remove melanoma that has spread to areas of skin far from the primary melanoma. Melanoma that spreads to the skin can cause new lumps. Sometimes these lumps bleed or cause discomfort. They can be removed under a local or general anaesthetic, depending on the amount of skin being removed.

You may have the operation as a day case. Or you may need to stay in hospital overnight. Some people need skin taken from another part of the body to replace the skin that is removed. This is called a skin graft. Your surgeon or specialist nurse will explain more about this.

Your stitches will be removed about a week after surgery. If you have dissolvable stitches, they will not need to be removed. Your wound may need to be cleaned and dressed until it has 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.

# Lymph nodes

Melanoma can spread to lymph nodes far away from the primary melanoma (page 6). The lymph nodes may become enlarged or feel hard. If this is uncomfortable or painful, you may have an operation to remove them.

You will have the operation under a general anaesthetic. You may be in hospital for a few days. The type of operation you have depends 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 (drain) to remove any fluid that builds up around your wound. The drain is connected to a small bottle. Your nurse will remove the drain when most of the extra fluid has drained away. This is usually within a few days. Some people go home with the drain in place. It can be removed by a practice nurse at your GP surgery or a district nurse at home.

The wound will be covered with a dressing. Your stitches or staples will be removed 7 to 10 days after the operation. If you have dissolvable stitches, they will not need to be removed. The hospital nurses can show you how to take care of your wound. Or they can arrange for a district nurse to do it for you at home.

If your lymph nodes have been removed, you may develop swelling in an arm, leg or other part of the body. This will depend on where in the body the lymph nodes were removed. This is called lymphoedema.

We have more information about how to reduce your risk of lymphoedema in our booklet **Understanding lymphoedema** (page 82).

## Brain

If melanoma has spread to the brain but nowhere else, your doctor may talk to you about having surgery. You may have surgery in combination with immunotherapy or targeted therapy (pages 34 to 39). A specialist surgeon called a neurosurgeon will explain whether an operation is possible.

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. You usually have steroid drugs to help reduce any swelling around the tumour and improve your symptoms. You usually have these before your operation and for a few weeks afterwards. If your surgeon cannot remove all the tumour, they will remove as much as they can.

You may have a type of radiotherapy called stereotactic radiosurgery after surgery to the brain (page 37).

## Liver or lungs

Surgery to remove secondary melanoma from the lungs or liver is a big operation. You may be in hospital for up to a week. But it may take several weeks or longer to recover. Your may have surgery after you have finished immunotherapy or targeted treatments. These may help to shrink the cancer.

An operation to remove secondary tumours in the liver is called a liver resection. It takes several hours and is done in a specialist liver unit. After surgery, the remaining liver can grow bigger and work as it did before. We have more infromation about liver resection on our website. Visit **macmillan.org.uk/secondary-liver-cancer**.

Surgery to the lung will depend on how much of the lung is affected. It may be a small section of the lung, or a larger area. Removing part of the lung will not affect your breathing.

# Other treatments

You may have other treatments to treat areas of skin or lymph nodes that cannot be removed with surgery. Some of these are only available at certain hospitals. Not all of them are available in every area of the UK. Your doctor or nurse can give you more information.

## T-VEC for melanoma

T-VEC (Imlygic®) is an immunotherapy drug that uses a virus to treat areas of melanoma that have spread to the skin or lymph nodes (pages 6 to 7). It is only used if melanoma has not spread to other areas such as the bones or brain.

The virus is designed to infect cancer cells. This helps your body's immune system find and destroy the area of melanoma that has been treated.

T-VEC is injected directly into the area of melanoma. You usually have this treatment every 2 weeks. Your cancer doctor will give you more information.

Common side effects include:

- tiredness
- tumour pain
- redness or inflammation at the injection site
- flu-like symptoms
- feeling sick
- headaches.

Your cancer doctor or specialist nurse will give you more information about side effects and managing them.

# Chemotherapy into a limb

You may have chemotherapy directly into a limb to treat clusters of melanoma in the arm or leg where the melanoma started. Chemotherapy into a limb is also called isolated limb perfusion (ILP) or isolated limb infusion (ILI). It allows chemotherapy, and sometimes another anti-cancer drug, to be given directly to a leg or arm. During the procedure, doctors use a tight band to stop blood flow in the limb. This is called a tourniquet. This stops the drugs getting into the rest of the body. You need to stay in hospital for a few days to have this treatment.

## Isolated limb perfusion (ILP)

ILP is given under a general anaesthetic. During ILP, the surgeon temporarily disconnects the blood flow between your affected limb and the rest of your body. The blood from your limb is circulated through an external pump and back into your limb. Oxygen is also added to the blood going to the limb. The chemotherapy drugs are given into the blood that circulates through your limb.

## Isolated limb infusion (ILI)

Isolated limb perfusion (ILI) may sometimes be used instead of ILP. With ILI, the blood does not circulate through a pump and no oxygen is added. Because of this, the tourniquet cannot be used for as long as an ILP. This reduces the amount of time that chemotherapy can circulate in the limb.

### After the procedure

The nurses and doctors will monitor you closely to make sure you do not have any complications. Any complications will usually be picked up early. You will have to rest and raise (elevate) your limb.

### Side effects

Your cancer doctor or specialist nurse will explain any side effects to you and tell you what to expect. Side effects usually get better after 6 to 8 weeks, but sometimes, they may last longer.

The side effects usually only affect the treated limb. You may get some pain in the limb and your muscles and joints might be inflamed. The limb may become red and swollen and occasionally the skin may blister.

Your cancer doctor and specialist nurse will give you more information and tell you what to expect about chemotherapy into a limb.

## Laser therapy

You may have laser therapy to destroy small areas of melanoma on the skin. The treatment involves directing a small, strong beam of light at the affected skin. This destroys the melanoma cells. You can have the treatment more than once. Some people will have several sessions to treat different areas of melanoma.

You can have laser therapy as an outpatient as a day case. You may be given a local anaesthetic to numb the area first. You may feel some discomfort in the skin during and after treatment. Your doctor may advise you to take mild painkillers to help. The treated area is usually covered with a dressing to protect it while it heals.

# Electrochemotherapy

Electrochemotherapy uses chemotherapy drugs (page 43) and a small electrical current to treat cancer cells.

The doctor injects a low dose of chemotherapy into the tumour or into a vein (intravenously). After this, they put a probe (electrode) directly over the tumour to give an electrical pulse. The pulse changes the outside layer of the cancer cells. This is called electroporation. It helps the chemotherapy get into the cancer cells and destroy them.

You can usually go home the same day. Some people stay in hospital overnight.

If you are having treatment to a single area, the doctor will give you a local anaesthetic to numb the area. They use a fine needle to inject the anaesthetic into the skin. If lots of areas are treated at the same time, you may have a general anaesthetic.

You may feel some discomfort in the skin after treatment. Your doctor may advise you to take mild painkillers to help. The treated area is usually covered with a dressing to protect it while it heals.

## Side effects

The side effects of electrochemotherapy are different to the side effects of chemotherapy. Electrochemotherapy only uses low doses of chemotherapy drugs. You may get some mild sickness or feel breathless. You may also get some side effects to the skin in the treated area. We have more information about electrochemotherapy on our website. Visit **macmillan.org.uk/electrochematherpy**

# Imiquimod

Imiquimod is a cream that uses your body's immune system to destroy cancer cells. You sometimes have it to treat small areas of melanoma on the skin. You spread the cream on the area of the melanoma. Your doctor or nurse will explain how to do this, and how often.

# Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about clincal trials on our website. Visit **macmillan.org.uk/clinical-trials**

# Taking part in a clinical trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part – page 32. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting samples of your blood or from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

# Support during and after treatment

## Follow-up

You will have regular follow-up appointments with your cancer doctor or specialist nurse. They will check whether you have any side effects and whether symptoms have improved. If you are having immunotherapy or targeted therapy, you may have regular scans to check how well treatment is working. You may have scans, x-rays or blood tests.

Your doctor or nurse can talk to you about symptoms or side effects to look out for. You will be given contact details for your specialist nurse. You can contact them for advice and support.

## Getting help and support

It is common to have different feelings during and after cancer treatment. Talking to your family and friends often helps. If you are feeling very anxious or depressed, tell your doctor or nurse. They may be able to refer you to a counsellor or psychologist for more expert support.

There are also organisations, such as Melanoma Focus and Melanoma UK, that offer information and support (page 89).

## Coping with a change in appearance

If melanoma comes back in the skin or lymph nodes, it may cause nodules or skin lesions. Some people may have visible scarring or skin changes. All this can affect body image. Talk to your nurse if this is a concern for you.

Some skin clinics have a make-up specialist who can give you advice on the best way to cover up scars. The British Association of Skin Camouflage provides information about camouflage make-up to cover up scars (page 84).

There are different things that can help to improve body image changes. We have more information in our booklet **Body image and cancer** (page 82).

## Effects on your sex life

Cancer and its treatment can also cause physical and emotional changes that may affect your sex life. There are ways to improve your sexual well-being and to manage any problems. We have more information about what may help in our booklet on **Cancer and sex** (page 82).

## Complementary therapies

Some people find complementary therapies can help improve their well-being. Certain therapies may help people cope with symptoms or side effects. Some hospitals or cancer support groups offer complementary therapies along with cancer treatments. These may include, massage, relaxation and visualisation. Tell your cancer doctor or specialist nurse if you are thinking of trying complementary therapies. This includes supplements or herbal medicines. Some of these may interact with targeted therapy or chemotherapy. We have more information in our booklet **Cancer and complementary therapies** (page 82).

# Living with advanced melanoma

# Coping with symptoms and side effects

Immunotherapy and targeted therapy drugs help people with advanced melanoma live longer (pages 34 to 39). There may be long periods when the cancer is under control and you can live your normal life. These drugs can also control symptoms, but they may take a few weeks to work. You can have other treatments to control symptoms along with your immunotherapy or targeted drugs.

Controlling symptoms is an important part of your care. Always tell your cancer doctor or specialist nurse about symptoms or side effects, as there are things they can do to help.

You may see a doctor or nurse who is an expert in helping control symptoms. They may be based in a hospital, or in the community as part of a palliative care team. Palliative care means treatment to manage symptoms and to improve your quality of life. It can be used at any stage of advanced cancer. Your GP or cancer doctor can arrange a referral.

If treatments are no longer controlling the cancer, you and your doctor may decide that your care should focus on palliative care only.

We have more information in our booklet **Coping with advanced cancer** (page 82).

# Managing symptoms

You will see your doctors and nurses at the hospital regularly for check-ups. Always tell them about any symptoms or side effects you have, so they can arrange the right treatment and help. If you have any worries between appointments, contact your specialist nurse or GP.

The symptoms you may have depend on where the melanoma has spread to (pages 8 to 11). Treating the secondary cancer will usually improve the symptoms.

## Lungs

If melanoma has spread to the lungs, you may:

- feel breathless
- have a build-up of fluid in the lining of the lungs – this is called pleural effusion.

Different drugs can help relieve breathlessness. If you have a pleural effusion, doctors can drain the fluid from the lung to improve your breathing. We have more information about treating the symptoms of secondary lung cancer. Visit **macmillan.org.uk/secondary-lung-cancer**

## Bones

If melanoma has spread to the bones, you may have bone problems. There are different ways these can be treated. If you have a painful area in a bone, a short course of radiotherapy can improve this (pages 40 to 42). Melanoma in the spine may press on the spinal cord and cause a condition called spinal cord compression. This is not common. If you do have symptoms of spinal cord compression , contact your doctor immediately as you may need urgent surgery or radiotherapy. Symptoms include:

- back or neck pain which might feel like a band around your chest or tummy
- muscle weakness
- numbness and weakness in the legs
- problems controlling your bladder or bowels.

## Brain

If melanoma spreads to the brain, you may:

- have headaches
- feel sick
- have a seizure (fit).

Treating the secondary cancer with stereotactic radiosurgery or immunotherapy will relieve the symptoms.

Doctors also usually prescribe steroids. These help reduce symptoms caused by a tumour increasing pressure inside the brain. Steroids reduce swelling and help you to feel better. Anti-epilepsy drugs can help control any seizures. We have more information on our website. Visit **macmillan.org.uk/secondary-brain-cancer**

### Liver

Secondary cancer in the liver may cause general symptoms such as:

- tiredness
- feeling sick
- eating difficulties.

Your doctor can prescribe anti-sickness drugs to treat sickness. Tiredness, eating difficulties or pain can also be managed. We have more information on our website. Visit **macmillan.org.uk/secondary-liver-cancer**

## General symptoms

Advanced melanoma may cause general symptoms.

### Tiredness (fatigue)

You may get tired more easily. This may be because of treatment side effects or the cancer itself. You may find some of these suggestions help you deal with day-to-day tasks:

- Try to get plenty of rest, but balance this with some activity if possible. Even regular, short walks can give you more energy and improve sleep.
- Pace yourself and plan your day so you save energy for the things you want to do.
- Ask family and friends to help with things around the house.

We have other helpful tips on managing fatigue in our booklet **Coping with fatigue (tiredness)** – page 82.

## Eating difficulties

If feeling sick is stopping you from eating, tell your doctor or nurse. They can prescribe anti-sickness drugs to control sickness.

Even if you have lost your appetite, try to keep eating well and have regular snacks. There are different supplement drinks to help make sure you get enough calories and nutrients. Some of these are available on prescription. Your doctor or nurse can refer you to a dietitian if you need more advice. We have more information in our booklet **Eating problems and cancer** (page 82).

## Pain

If you have pain, your doctor can give you different types of painkiller to control it. Some are better for certain types of pain. Your doctor or specialist nurse will advise you on the best painkillers for you.

You need to take painkillers regularly, at set times of the day, rather than just when you feel pain. This stops pain building up and keeps it better controlled.

Many painkillers can cause constipation. It is important to eat foods high in fibre and to drink plenty of fluids. Your doctor can also give you laxatives to help.

If the cancer has spread to the bone and is causing pain, you can usually have a short course of radiotherapy to relieve it.

We have more information about painkillers and other ways of managing pain in our booklet **Managing cancer pain** (page 82).

## Lymphoedema

If the melanoma has spread to the lymph nodes in the groin or under the arm, you may develop swelling in your leg, arm or other part of the body. This is called lymphoedema. It may also happen as a side effect of surgery to remove the lymph nodes.

The lymph nodes help drain a fluid called lymph. It travels along fine tubes (lymphatic vessels) connecting the lymph nodes. Melanoma cells can block the flow of lymph. If this happens, fluid collects in the tissues under the skin, making your leg or arm swell.

If you notice any swelling, always tell your doctor or nurse straight away. There are different ways lymphoedema can be managed, including pressure garments, massage or surgery.

We have more information in our booklet **Understanding lymphoedema** (page 82).

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

# Your feelings and relationships

> "Writing a blog has allowed me to connect with people going through similar journeys online, which provides great comfort."

Jolene

# Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 82).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on pages 86 to 87 about other ways we can help you.

# Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklet **Talking about cancer** and **Cancer and relationships: support for partners, families and friends** (page 82).

## If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet **Talking with someone who has cancer** (page 82).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer** (page 82).

## Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer (page 91).

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 82).

> **"I didn't want to overly worry my children, but I also wanted to be open with them. When I did tell them, my son contacted a Macmillan nurse to ask some questions that he felt he couldn't ask me."**
>
> Anthea, diagnosed with advanced melanoma

# Financial support and work

> “When I got my cancer diagnosis I instantly worried about how this will affect my family, especially my children. But your mind quickly jumps to work, how you will pay the bills and mortgage. People tell you not to worry about work and money but you do.”

Sally, diagnosed with advanced melanoma

# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 84 to 87).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 94 to 95).

Our booklet **Help with the cost of cancer** has lots more information (page 82). You can find out about the ways Macmillan can support you on pages 84 to 87.

# Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

# Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**. Our Online Community forum on **Travel insurance** may also be helpful, visit **macmillan.org.uk/community**

# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (page 82).

There is also lots more information online at **macmillan.org.uk/work**

> **"I do get tired, it does affect my life. I decided reduce my hours at work, which has helped a lot."**
>
> Anthea, diagnosed with advanced melanoma

# Further information

# 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 booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

## Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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**

If you would 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**.

## The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

## 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 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

### Financial guidance

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

### Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

### 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 find out more about Macmillan Grants.

## Help with work and cancer

Whether you are 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**

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

## 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 is why we help bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

### 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**

You can also use our Ask an Expert service on the Online Community. You  can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

## Macmillan healthcare professionals

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.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## Melanoma support organisations

### The British Association of Dermatologists (BAD)

**www.skinhealthinfo.org.uk**
Online information and advice about living with a skin condition.

### The British Association of Skin Camouflage

**www.skin-camouflage.net**
Online information about using skin camouflage products to cover skin conditions or scarring.

### Changing Faces

Support line **0300 012 0275**
**www.changingfaces.org.uk**
Information and support for people living with a visible difference, and their family and friends. Offers a skin camouflage service at locations across the UK.

### Melanoma Focus

Melanoma helpline **0808 801 0777**
**www.melanomafocus.org**
Information, guidance and support for patients, carers and healthcare professionals. It provides a free helpline answered by expert skin nurses and The Melanoma TrialFinder of melanoma trials in the UK.

### Melanoma UK

Support line **0808 171 2455**
**www.melanomauk.org.uk**
Support and information for patients, carers and healthcare professionals. It provides a skin check toolkit.

## General cancer support organisations

### Cancer Black Care

Tel **020 8961 4151**
**www.cancerblackcare.org.uk**
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

### Cancer Focus Northern Ireland

Helpline **0800 783 3339**
**www.cancerfocusni.org**
Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK

Helpline **0808 800 4040**
**www.cancerresearchuk.org**
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland

Tel **0800 652 4531**
**www.cancersupportscotland.org**
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Macmillan Cancer Voices

**www.macmillan.org.uk/cancervoices**
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

### Maggie's

Tel **0300 123 1801**
**www.maggies.org**
Has a network of centres in many 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.

### Penny Brohn UK

Helpline **0303 3000 118**
**www.pennybrohn.org.uk**
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### Riprap

**www.riprap.org.uk**
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

### Tenovus

Helpline **0808 808 1010**
**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, benefits advice and an online 'Ask the nurse' service.

## General health information

### Health and Social Care in Northern Ireland

**www.northerntrust.hscni.net**
Provides information about health and social care services in Northern Ireland.

### NHS.UK

**www.nhs.uk**
The UK's biggest health information website. Has service information for England.

### NHS 111 Wales

**111.wales.nhs.uk**
NHS health information site for Wales

### NHS Inform

Helpline **0800 22 44 88**
**www.nhsinform.scot**
NHS health information site for Scotland.

### Patient UK

**www.patient.info**
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

## Counselling

### British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
**www.bacp.co.uk**
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

### UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
**www.psychotherapy.org.uk**
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### Mind

Helpline **0300 123 3393**
**www.mind.org.uk**
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
**www.samaritans.org**
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
**www.nidirect.gov.uk/money-tax-and-benefits**
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
**www.gov.uk/carers-allowance**
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

### England

Helpline **0800 144 8848**
**www.citizensadvice.org.uk**

### Scotland

Helpline **0800 028 1456**
**www.cas.org.uk**

### Wales

Helpline **0800 702 2020**
**www.citizensadvice.org.uk/wales**

### Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
**www.gov.uk/civil-legal-advice**
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

### Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
**nidirect.gov.uk/contacts/disability-and-carers-service**
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

### GOV.UK

**www.gov.uk**
Has information about social security benefits and public services in England, Scotland and Wales. Equipment and advice on living with a disability

### British Red Cross

Tel **0344 871 11 11**
Email **contactus@redcross.org.uk**
**www.redcross.org.uk**
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### Disability Rights UK

Tel **0330 995 0400** (not an advice line)
**www.disabilityrightsuk.org**
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

### Motability Scheme

Tel **0300 456 4566**
**www.motability.co.uk**
The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

## Support for young people

### Young Lives vs Cancer

Tel **0300 330 0803**
**www.younglivesvscancer.org.uk**
Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

### Teenage Cancer Trust

Tel **0207 612 0370**
**www.teenagecancertrust.org**
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

## LGBT-specific support

### LGBT Foundation

Tel **0345 330 3030**
**www.lgbt.foundation**
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### Live Through This

**www.livethroughthis.co.uk**
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

## Support for carers

### Carers Trust

Tel **0300 772 9600**
**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**
Helpline (Northern Ireland) **028 9043 9843**
**www.carersuk.org**
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

## 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 and Analysis Service

Tel **0207 654 8000**
**www.ndrs.nhs.uk**
Tel (Ireland) **0214 318 014**
**www.ncri.ie** (Ireland)

### Scottish Cancer Registry

**www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy**

### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
**phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu**

### Northern Ireland Cancer Registry

Tel **0289 097 6028**
**www.qub.ac.uk/research-centres/nicr**

# Your 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, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Samra Turajlic, Consultant Medical Oncologist.

With thanks to:

Donna Begg, Clinical Nurse Specialist; Sharon Cowell-Smith, Macmillan Advanced Nurse Practitioner Skin Cancers; Dr Sarah Danson, Medical Oncologist; Mr Amer Durrani, Consultant Plastic and Reconstructive Surgeon; Mr David Mowatt, Oncological Plastic Surgeon; and Dr Ben Shum, Medical Oncologist.

Thanks also to the other professionals and the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

## Sources

Below is a sample of the sources used in our melanoma information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Keilholz U, Ascierto PA, Dummer R, et al. ESMO consensus conference recommendations on the management of metastatic melanoma: under the auspices of the ESMO Guidelines Committee. Annals of Oncology. 2020. 31 (11): 1435–1448 [accessed May 2022].

Peach H, Board R, Cook M, et al. Current role of sentinel lymph node biopsy in the management of cutaneous melanoma: A UK consensus statement. Journal of Plastic, Reconstructive & Aesthetic Surgery. 2020. 73 (1): 36–42 [accessed May 2022].

# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

## 5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

## 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

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

## Do not 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 would rather donate online go to **macmillan.org.uk/donate**

Registered with
FUNDRAISING
REGULATOR

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

MACMILLAN
CANCER SUPPORT

**This booklet is about a type of skin cancer called melanoma. It is for anyone who has melanoma that has spread to another area of the body. This is called advanced or metastatic melanoma. There is also information for carers, family members and friends.**

---

The booklet talks about advanced melanoma. It explains how melanoma is diagnosed and how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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.

---

Trusted Information Creator
*Patient Information Forum*

© Macmillan Cancer Support, November 2022. 5th edition. **MAC12179_E05_R**. Next planned review November 2025. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.