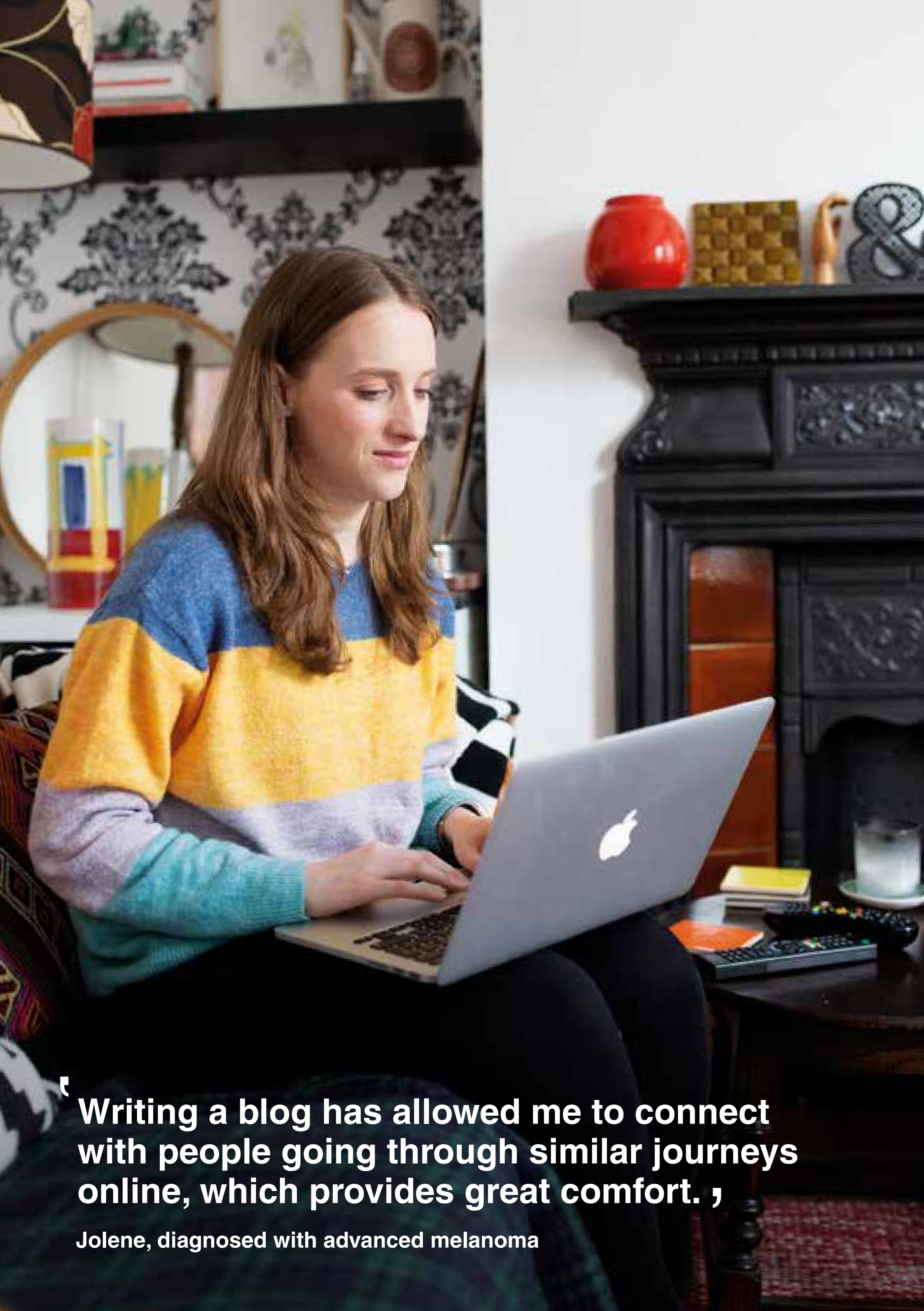
MACMILLAN
CANCER SUPPORT

UNDERSTANDING ADVANCED MELANOMA



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

Jolene, diagnosed with advanced melanoma

About this booklet

This booklet is about melanoma. It is for anyone who has melanoma that has spread to another area of the body (advanced melanoma). There is also information for carers, family members and friends.

The booklet explains melanoma that has spread to another area (advanced or metastatic melanoma). It has information about how advanced melanoma is diagnosed and treatment options. It also has information about managing symptoms and coping with the emotional effects.

We hope this booklet 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.

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 98 to 110, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see pages 111 to 113).

Quotes

In this booklet, we have included quotes from people who have had advanced melanoma, which you may find helpful. Some are from our Online Community – **macmillan.org.uk/community** The others 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 type of skin cancer that develops from cells called **melanocytes**. These cells give our skin its colour.

Most melanomas can be successfully treated. But sometimes melanoma can come back after treatment. This may be a few months after treatment, or sometimes many years later. For some people the melanoma may be advanced when it is first diagnosed.

In advanced melanoma, the melanoma cells have spread from where the cancer first started (the primary site) to other parts of the body. Melanoma cells can travel through the blood 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.

When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

The secondary cancer is made up of melanoma cells and the treatments doctors use are for melanoma. So a secondary melanoma tumour in the lung is treated as melanoma, not as lung cancer.

In advanced melanoma, the melanoma cells have spread to another part of the body. Melanoma can spread to any part of the body, but the most common areas in advanced melanoma are:

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

> ‘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**

Signs and symptoms

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

A small number of people who have not had melanoma before may develop symptoms of secondary melanoma. 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 the melanoma has spread to. We describe them over the next few pages.

The lymph nodes

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

The skin

Secondary tumours in the skin, often appear as firm or hard lumps (nodules). They can sometimes appear as a flat grey or purple area.

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 about secondary cancer in the lungs, pleural effusion and coping with breathlessness (see page 94).

The liver

Cancer cells that spread to the liver can cause:

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

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. The earlier MSCC is diagnosed, the better the chances are of treatment helping. If you cannot contact your specialist team, you should go to your local accident and emergency department straight away.

Our booklet **Understanding secondary cancer in the bone** has more information (see page 94). There is also more information about MSCC on our website – visit **macmillan.org.uk/mscc**

The brain

Secondary cancer in the brain may cause headaches and sickness. These may 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 also have seizures (fits) or a change in their personality.

There is more information about secondary cancer in the brain on our website – visit **macmillan.org.uk**

The digestive system

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

- pain in the tummy (abdomen)
- a change in bowel function (constipation or diarrhoea)
- sickness (vomiting)
- blood in or on your poo (stools)
- unexplained tiredness caused by low red blood cells (anaemia).

General symptoms

The general symptoms of advanced melanoma can include:

- weight loss
- loss of appetite
- feeling very 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.

> ‘The main symptom I currently have is fatigue. I have to plan my time effectively in order to make sure I am not overly tired. Each day varies. I become especially tired straight after treatment.’
>
> **Jolene**

DIAGNOSING ADVANCED MELANOMA

How advanced melanoma is diagnosed

If you have already had treatment for melanoma, you may still be going to clinics for check-ups. Sometimes advanced melanoma will be found at one of these appointments, before you have any symptoms.

If you notice new symptoms between appointments, contact your cancer specialist. They may arrange some tests for you. Do not wait until your next appointment.

Rarely, some people have melanoma that is advanced without having found the original melanoma on the skin (primary).

Sometimes, melanoma has already begun to spread when it is first diagnosed. When the melanoma is first removed, your doctor will check the nearest lymph nodes. They may recommend taking a sample from the nearest lymph node if:

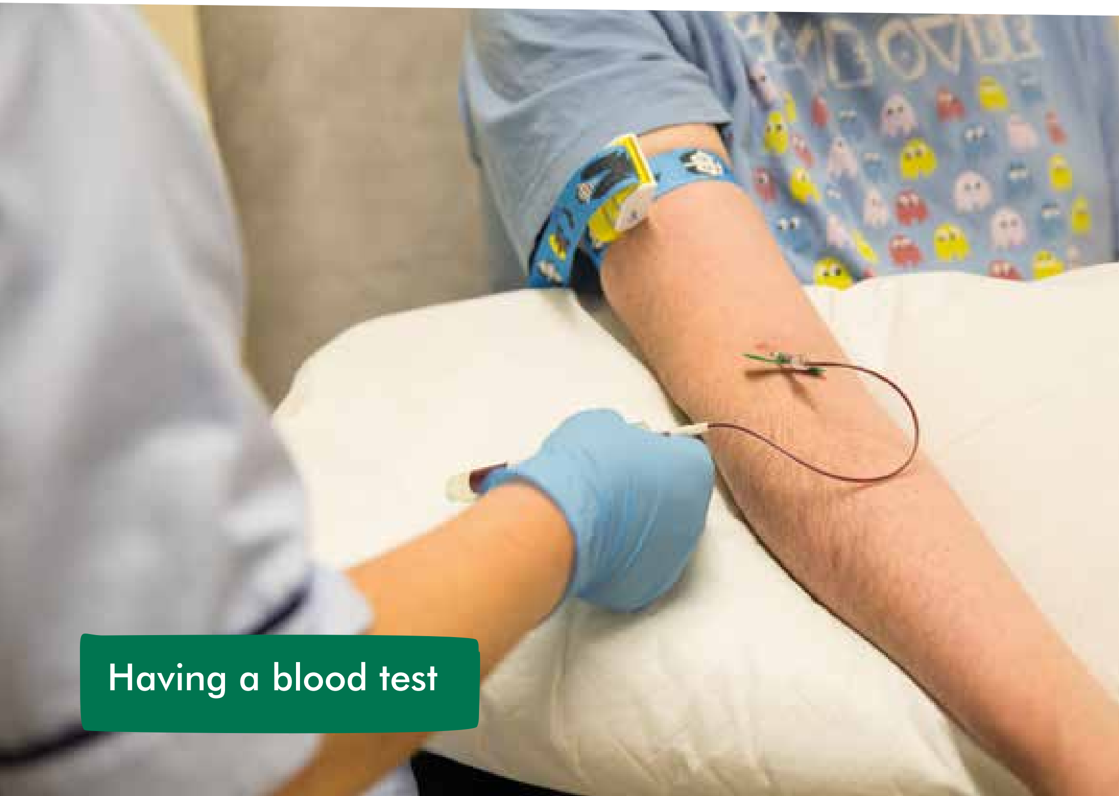
- the lymph nodes are swollen
- the doctor thinks the melanoma may have spread to the lymph nodes.

This is called a sentinel lymph node biopsy. We have more information in our booklet **Understanding melanoma - lymph node assessment and treatment** (see page 94).

The sample may show there are melanoma cells in the lymph nodes. Or you may have symptoms that suggest the melanoma has spread elsewhere. In this situation your doctor may arrange further tests. These will depend on your symptoms. You may have some of the following tests.

Blood tests

Your doctor may take a blood sample to check your general health. They will also check how well your kidneys and liver are working.



Having a blood test

CT 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 to 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 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 is 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 will probably be able to go home as soon as the scan is over.

Chest x-ray

This uses x-rays to take a picture of your chest, to check your lungs and heart.

A CT scanner

MRI 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 is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have 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 is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not 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 will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will 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 tummy area (abdomen), liver or pelvis.

If you are having an ultrasound of your pelvis, the ultrasound staff will ask you to drink plenty of fluids. This is so that your bladder is full for the scan. This helps to give a clearer picture. They will then spread a gel onto your abdomen and gently rub a small, microphone-like device over the area. This produces sound waves, which 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 3 hours after having the injection before you have the 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 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 the scan. Areas of cancer are normally more active than surrounding tissue and absorb more of the sugar. This 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 102 to 103 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

> ‘The scan showed melanoma was back. I had a single lesion in my brain which would need to be removed by surgery before the lung tumour could be tackled. The melanoma had spread. I couldn’t be cured of cancer, but would be offered treatment to help manage my symptoms and hopefully extend my life for as long as possible.’
>
> **Jolene**

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** To find details about the cancer registry in your area, see page 101.

TREATING ADVANCED MELANOMA

Treatment overview

When melanoma has spread to other parts of the body, the aim of treatment is usually 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 cancer or stopping it growing for a time. Newer treatments mean many people are living a long time with advanced melanoma.

Depending on your situation, you may have one or more types of treatment.

The main treatments for advanced melanoma are:

- immunotherapy and targeted therapies to help control or shrink the growth of advanced melanoma (see pages 33 to 39)
- radiotherapy to help control symptoms if melanoma has spread to the brain, liver, bones or skin (see pages 40 to 42).

Other treatments that are sometimes used are:

- chemotherapy (see pages 43 to 44)
- surgery, which is sometimes used to remove a secondary tumour if it is small and only in one place – this can help control symptoms, or rarely it may cure the melanoma (see pages 45 to 48).

Metastases (secondary cancers) in the skin may sometimes be treated with:

- laser therapy (see page 50)
- electrochemotherapy (see pages 54 to 55)
- chemotherapy into a limb (see pages 51 to 53).

How treatment is planned

A team of specialists will meet to discuss the results of your tests and plan your treatment. They are called a multidisciplinary team (MDT). The MDT may include:

- a dermatologist – a doctor who specialises in treating skin cancers and skin disorders
- a plastic surgeon – a doctor who specialises in reconstructive surgery
- a specialist surgeon – this will depend on which area of the body the cancer has spread to
- a medical oncologist – a doctor who specialises in chemotherapy, immunotherapy and targeted therapy drugs
- a clinical oncologist – a doctor who specialises in radiotherapy and chemotherapy
- a pathologist – a doctor who examines samples from the tumour to see whether it is a cancer and, if so, which type
- a skin cancer specialist nurse (CNS) – a 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, research nurse, dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

Your specialist will talk to you about which treatment may be suitable for you. This may depend on:

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

They will also take your own wishes into consideration.

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 do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is 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 is 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 do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not 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

Your doctors may offer you a choice of treatments. This happens when two or more treatments work as well as each other and there is no clear advantage of one treatment over another. Make sure you have enough information about the different treatments, 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 you do not understand or feel worried about. It may help to talk about the benefits and disadvantages of different treatments with your cancer specialist or specialist nurse.

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.

There may be a time when treatment has little effect on the cancer, and you will get the side effects without any benefit. Making treatment decisions in these circumstances is always hard. You may want to talk about it carefully with your cancer doctor, specialist nurse and family or friends.

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

Questions you could ask your specialist

It often helps to take a relative or close friend with you to your appointments. They can support you, take notes for you, or remind you of any questions you want to ask.

It may help to make a list of questions before your next appointment (see pages 111 to 113). Here are some questions you might want to ask your doctor:

- What are my treatment options?
- What is the aim of the treatment?
- How long will it be before I feel the benefit of any treatment?
- How long will I have treatment for?
- 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 you do not have to keep repeating information.

We have more information about your choices in our booklet **Making treatment decisions** (see page 94).

Immunotherapies and targeted therapies

Immunotherapies

The immune system protects the body against illness and infection. Immunotherapies are treatments that use the immune system to recognise and kill cancer cells.

There are different types of immunotherapy that work in different ways. The main drugs used to treat advanced melanoma are:

- ipilimumab
- nivolumab
- pembrolizumab.

These drugs are sometimes called check-point inhibitors.

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 T-cells stops this happening. Ipilimumab blocks this protein, so the T-cells can destroy melanoma cells. It can help shrink or slow the growth of advanced melanoma. You have ipilimumab as an infusion (drip) into a vein.

Some common side effects include:

- tiredness (fatigue)
- diarrhoea
- a skin rash
- itching.

We can send you information about how to manage these side effects (see page 94).

Pembrolizumab and nivolumab

Pembrolizumab (Keytruda®) and nivolumab (OPDIVO®) both target a protein called a PD-1 receptor, which switches off T-cells. T-cells are part of the immune system. They fight infection and disease. The drugs attach to the receptor, so the T-cells cannot be switched off. This keeps the T-cells active. It may help shrink a tumour or stop it growing.

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

Some common side effects include:

- diarrhoea
- tiredness (fatigue)
- a skin rash
- changes to the thyroid gland (making too much or too little of a hormone called thyroxine)
- inflammation of the liver (hepatitis).

We can send you more information about how to manage these side effects (see page 94).

Nivolumab may be given together with ipilimumab. Your cancer doctor or specialist nurse will give you more information about these treatments if they are suitable for you.

> ‘My experience of immunotherapy has been positive. Although I still struggle with fatigue, the symptoms are less severe than when I had other treatments.’
>
> **Jolene**

Important side effects of immunotherapy

Nivolumab, pembrolizumab and ipilimumab can cause inflammation in many different parts of the body. This can include the bowel, liver, kidneys, skin and eyes. They can also affect the endocrine system (which makes hormones), the heart, the lungs and the nervous system.

This can sometimes cause more serious side effects, including:

- diarrhoea that does not get better
- changes in the way the liver works
- skin rashes and blisters
- blurred or double vision
- feeling very tired.

If you notice these side effects, or any other new side effects, tell your doctor or specialist nurse straight away. They will usually give you steroids to help reduce the inflammation. If your side effects are severe, they may recommend delaying or sometimes stopping the treatment.

This treatment may also cause delayed side effects. These can start weeks, months, or sometimes more than a year, after you finish treatment.

We have more information about steroids that you might find useful – visit **macmillan.org.uk/steroids**

T-VEC

T-VEC (Imlygic®) is a newer immunotherapy drug sometimes used to treat melanoma. It may be used if the melanoma has spread to the skin or the lymph nodes further away. But it is not suitable if the melanoma has spread to areas such as the bones or the brain.

T-VEC is given by injection directly into the melanoma.

Some common side effects include:

- tiredness
- tumour pain
- flu-like symptoms
- headaches.

We can send you more information about how to manage these side effects (see page 94). T-VEC may only be available in some situations. Your cancer doctor or specialist nurse will give you more information about this treatment if it is suitable for you.

Targeted therapies

Targeted therapy uses drugs or other substances to find and attack melanoma cells that contain certain gene changes (mutations). Your doctor will check if your melanoma has a specific mutation before they can offer you this treatment.

There are different types of targeted therapy. Each type 'targets' something in or around the cancer cell that is helping it grow and survive.

Cancer growth inhibitors

Cancer growth inhibitors block the signals that tell cells in the body to develop and divide. Your specialist may recommend treatment with a cancer growth inhibitor if the cancer has a specific change (mutation) in a gene called BRAF.

BRAF helps control proteins 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 that was removed during diagnosis or surgery (see pages 45 to 48). Different cancer growth inhibitors work in slightly different ways. These types of drug do not work for people with melanoma that does not have the BRAF gene mutation.

The main cancer growth inhibitors used to treat advanced melanoma are:

- dabrafenib (Tafinlar®)
- trametinib (Mekinist®).

These drugs are often given together. You take them as tablets. The drugs have some similar side effects, and some that are different. Your doctor or nurse can tell you more about these drugs and whether they are suitable for you.

Common side effects of them both include:

- skin changes
- feeling or being sick
- loss of appetite
- diarrhoea or constipation
- tiredness
- joint pain
- fever.

There are also two newer targeted therapy drugs that may be available to treat advanced melanoma. These are called encorafenib and binimetinib. They are only helpful for people with the BRAF mutation. Your cancer doctor or nurse can tell you more about these drugs.

We have more helpful information about how to take the drugs and the different side effects on our website – visit **macmillan.org.uk/dabrafenib-with-trametinib**

We can also send you our booklets **Coping with fatigue (tiredness), Managing cancer pain** and **Eating problems and cancer** (see page 94).

Clinical trials

There may be clinical trials looking at new immunotherapy or targeted therapy drugs to treat advanced melanoma (see pages 56 to 58). Some of these trials test different combinations of drugs. This is to see whether the combination works better than one drug given alone.

Research is also looking at cancer vaccines. If there are clinical trials testing these or other drugs, your team will give you more information about them.

Radiotherapy

Radiotherapy uses high-energy rays, such as x-rays, to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. It is usually given as a series of short, daily treatments in the radiotherapy department. The radiotherapy machine looks similar to a big x-ray machine.

Some normal cells in the area can also be damaged by radiotherapy. This can cause side effects (see page 42). These normal cells can usually repair themselves, but cancer cells cannot. As the normal cells recover, the side effects usually get better.

For advanced melanoma, radiotherapy is often given to help reduce pain and improve other symptoms. This is called palliative radiotherapy, because it is given to ease symptoms.

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

- **The skin or lymph nodes further away from the original melanoma** – radiotherapy is sometimes used to help reduce the size of lymph nodes or skin nodules and improve symptoms, such as pain.
- **The bones** – radiotherapy can help reduce bone pain and swelling.
- **The brain** – radiotherapy can help shrink a secondary cancer in the brain and improve symptoms. Your doctors might suggest a newer radiotherapy technique called stereotactic radiosurgery (SRS).

You may need only a few sessions, or a short course of treatment. Your doctor will talk to you about your treatment plan and the 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.

There is lots more information you might find helpful in our booklet **Understanding radiotherapy** (see page 94).

Having external beam radiotherapy

Side effects of radiotherapy

Radiotherapy will make you feel tired. This can last for some weeks after your treatment finishes.

Other side effects depend on the part of your body being treated and how much radiotherapy you are having. Usually when you are having radiotherapy to improve symptoms, the side effects are milder. This is especially true if you only have 1 or 2 treatments.

We have more information about radiotherapy for secondary bone cancer in our booklets **Coping with fatigue**, **Understanding radiotherapy** and **Understanding secondary cancer in the bone** (see page 94).

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 it if other treatments such as immunotherapies and targeted therapies are not suitable or no longer work (see pages 37 to 38).

Chemotherapy may help control or slow the growth of the melanoma 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).

There is lots more information about chemotherapy in our booklet **Understanding chemotherapy** (see page 94).

How chemotherapy is given

You usually have chemotherapy drugs as an injection into a vein (intravenously), or sometimes by mouth (orally). You may have only one drug, or a combination, depending on your situation.

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

Side effects of chemotherapy

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's planned for you.

Surgery

Surgery is used to help control advanced melanoma and relieve symptoms. It is usually only possible if the melanoma has spread to:

- areas of skin distant from the original melanoma
- lymph nodes distant from the original melanoma.

Surgery can sometimes be used to remove melanoma that has spread to the:

- brain
- liver (but only if the melanoma is in one place in the liver)
- lungs (but only if the melanoma is in one place in the lungs).

Melanoma that has spread to the skin

Surgery can remove a melanoma that has spread to the skin. Melanoma that spreads to the skin can cause new lumps. Sometimes these lumps bleed or cause discomfort. Lumps can be removed under local or general anaesthetic, depending on the amount of skin being removed.

You may have the operation as an outpatient or you may stay in hospital overnight. Some people need to have skin taken from somewhere else on 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. You may need to have your wound 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.

Melanoma that has spread to the lymph nodes

Melanoma can spread to lymph nodes far away from the melanoma. 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 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 bottle. The drain is removed when most of the extra fluid has drained away, usually within a few days. Some people may 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.

> ‘I had to have full groin clearance surgery to remove as many lymph nodes as possible. They would all be checked for cancer.’
>
> **Kathryn**

The wound will be covered with a dressing and your stitches or staples will be removed 7 to 10 days later. 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, there is a risk of developing swelling in an arm, leg or other part of the body. It 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 (see page 69).

Melanoma that has spread to the brain

Surgery to remove melanoma that has spread to the brain may be possible if there is only one tumour. It will only be offered if melanoma has not spread anywhere else in the body. A specialist surgeon (a neurosurgeon) can talk to you about whether an operation is possible. Your melanoma specialist will refer you if they think surgery could help.

This type of surgery is 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.

You usually have steroid drugs to help reduce any swelling around the tumour and improve your symptoms. These are usually prescribed before your operation and for a few weeks afterwards. Some people may have radiotherapy after surgery to the brain.

Melanoma that has spread to other parts of the body

If the melanoma has spread to the liver or lungs, it may be possible to remove the tumour with surgery if:

- it is only a single tumour or area of the liver or lungs
- melanoma has not spread anywhere else in the body.

Surgery to remove tumours from the lungs or liver is a big operation. It is unlikely to cure the cancer. Your specialist will talk with you about the risks and possible benefits of the operation. They will usually refer you to a specialist surgeon. The surgeon will do some checks to find out whether an operation is suitable for you.

Other treatments

If you have a lot of melanomas in the skin (nodules), it may be hard to remove them all with surgery or treat them all with radiotherapy (see pages 42 to 51). In this situation, your specialist may advise some other treatments. This might be to help shrink the melanomas or to relieve symptoms such as pain or bleeding. You usually have these treatments in specialist centres.

Laser therapy

A treatment called carbon dioxide (CO2) laser therapy can be used to help shrink advanced melanoma and to relieve symptoms. It involves directing a high-intensity beam of light at the affected areas of the skin to destroy the melanoma cells.

You can have this treatment as an outpatient. You can have it more than once. You may be given a local anaesthetic to numb the area first. You may feel some discomfort in the skin during and after treatment. Taking mild painkillers can help. The area may be covered with a dressing to protect it afterwards.

Talk to your doctor or nurse if you have any questions about this treatment.

Chemotherapy into a limb

Chemotherapy can be given directly into a limb. This is called regional chemotherapy. It 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 used if the melanoma has not spread anywhere else in the body.

There are two ways of giving chemotherapy into a limb:

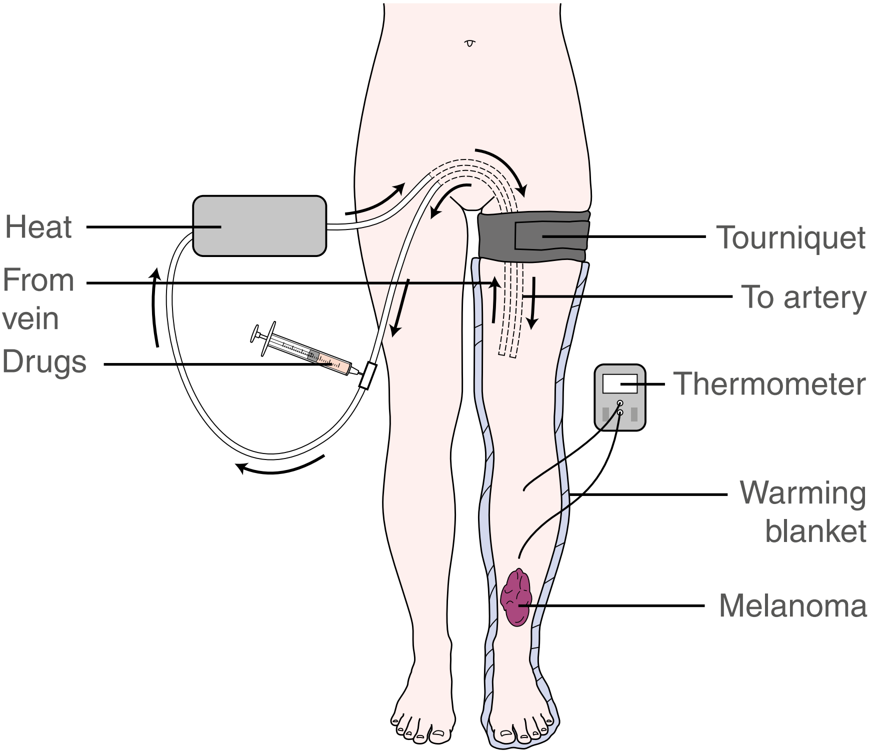
- isolated limb perfusion (ILP) (see page 53)
- isolated limb infusion (ILI) (see page 52).

These treatments are only done in some specialist UK centres. You have them under general anaesthetic. You stay in hospital for 3 to 7 days.

A surgeon disconnects the blood flow to your limb from the rest of your body. They give chemotherapy (anti-cancer) drugs into the blood that circulates through the limb. A tourniquet stops the drugs going into the rest of the body. The surgeon flushes the drugs out of the limb before reconnecting the blood supply.

With ILP, the blood circulates through a pump that adds oxygen to the blood. A pump is not used with ILI. ILI is used more often than ILP.

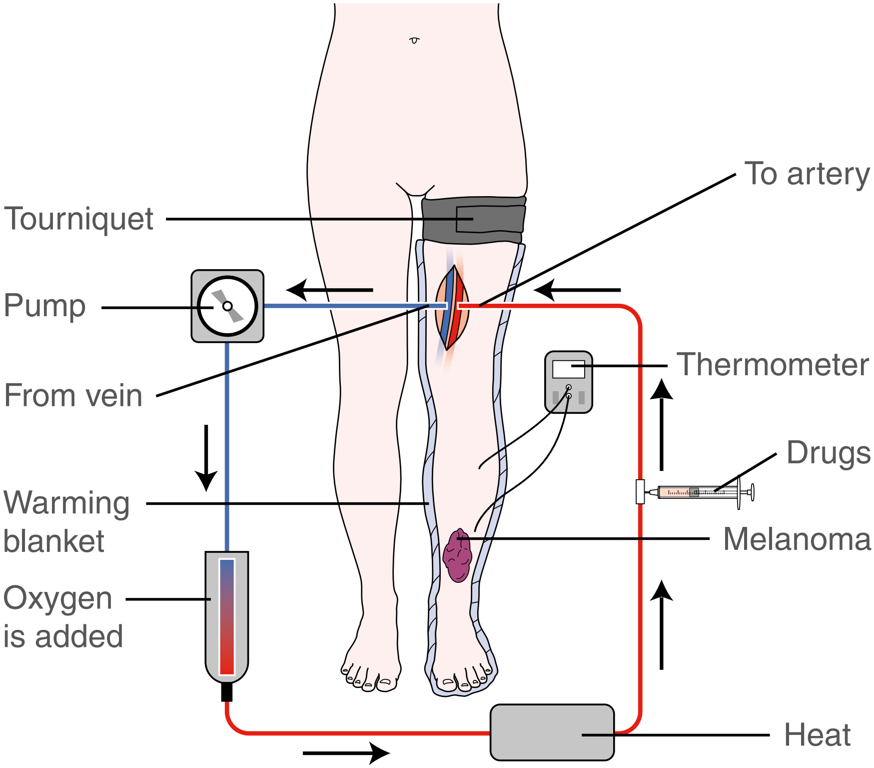
Isolated limb infusion



After the procedure, your nurse will closely monitor your limb and make sure your blood flow is normal.

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 6 to 8 weeks, but in some people they 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 perfusion



We have more information about having chemotherapy into a limb on our website – visit **macmillan.org.uk/chemotherapy**

Electrochemotherapy

Electrochemotherapy is used to treat cancers on the skin. It can help control symptoms when other treatments are no longer working.

Electrochemotherapy uses chemotherapy and a small electrical current to treat cancer cells. The doctor injects a low dose of chemotherapy into the melanoma or into a vein (intravenously). Then they usually put an electrode directly over the melanoma to give the electrical pulse. The pulse changes the outside layer of the cells. This helps the chemotherapy get into the cancer cells and destroy them.

If you are having an injection into a single area of melanoma, the doctor will give you a local anaesthetic first. This will numb the area. If they are treating lots of areas at the same time, they may use a general anaesthetic. This means you will be asleep. Treatment takes between 10 and 60 minutes.

You usually have electrochemotherapy as an outpatient, but you may stay in hospital overnight. Sometimes you can have the treatment more than once.

Because it is a newer treatment, it is not yet widely available. Your doctor or specialist nurse can 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 the 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. These slightly change the way they give the treatment, which can help. The contractions will stop after the treatment finishes.

Other side effects include redness and swelling in the treated area, a rash and scarring. The chemotherapy may cause mild sickness. Your doctor or nurse will tell you more about the possible side effects.

We have more information about how to manage these side effects on our website – visit **macmillan.org.uk/sideeffects**

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

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.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials).** We can send you a free copy (see page 94).

Blood and tumour samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

Follow-up

After your treatment, you will have regular follow-up appointments with your cancer specialist or specialist nurse. They will check whether you have any side effects after treatment, and that symptoms have improved. You may have scans, x-rays or blood tests. They will also show you how to check your skin for any changes. You will be given contact details for your specialist nurse. You can contact them any time for advice and support.

> ‘I am having three-monthly skin check-ups and six-monthly scans.’
>
> **Sharon**

Many people find they get anxious before appointments. This is natural, and it may help to talk to someone. If you notice any new symptoms in between appointments, let your doctor know as soon as possible. We have more information that might help in our booklets **Your feelings after cancer treatment** and **Talking about cancer** (see page 94).

> ‘I see my Macmillan nurse regularly at my oncology appointments. I am often in email contact with her about my appointments or upcoming scans.’
>
> **Jolene**

LIVING WITH ADVANCED MELANOMA

Coping with symptoms and side effects

Your doctors and nurses at the hospital or your GP practice will regularly check how you are feeling. They will check whether you are having any symptoms or side effects. It is important to tell your medical team how you are. This is so they can arrange the right treatment and help. You can also contact your specialist nurse if you have any worries.

For some people, treatment may no longer be controlling the cancer. In this situation, your doctor may suggest trying to ease symptoms rather than trying to shrink the cancer. 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 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 may experience and some ways of relieving them.

We have more useful information about controlling symptoms and side effects of advanced cancer in our booklet **Coping with advanced cancer** (see page 94).

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 you can do the things you want to do most. You may find some of these suggestions help you deal with day-to-day 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. Eat small meals and snacks throughout the day.
- Have a bath instead of a shower.
- Try to wear clothes that are easy to put on and 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 can also be useful, such as walking sticks, walking frames or wheelchairs. 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 in our booklet **Coping with fatigue** (see page 94).

Eating changes

You may notice changes in your eating habits. The cancer and its treatment can cause problems, such as:

- loss of appetite
- changes in the way you smell and taste food
- difficulty swallowing
- feeling sick (nausea).

Even if you are eating well, you may still lose weight and muscle. This is 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. This can be easier than having three large meals a day.
- Choose foods you enjoy.
- If you can only eat small amounts, choose foods or drinks that will give you energy and protein. This means you will get the most out of what you eat.
- If you do not 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. We also have recipes you could try.
- 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 in our booklets **Recipes for people affected by cancer**, **Eating problems and cancer** and **Healthy eating and cancer** (see page 94).

Feeling sick or being sick

Some treatments for advanced melanoma cause sickness (nausea). Sometimes the melanoma itself may make you feel sick. This can often be relieved by anti-sickness tablets.

There are different types of anti-sickness medicine available. Your doctor will find the one that suits you best. Steroids are often used. These can help relieve sickness and give you more energy. They can also improve your appetite.

We have information about controlling nausea and vomiting on our website – visit **macmillan.org.uk**

Pain

Not everyone with cancer gets pain. If you have pain, there are many different types of painkiller your doctor can give you 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.

Your doctor will usually give you painkillers to take regularly, at set times of the day, rather than just when you need them. Taking them regularly stops 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 give you laxatives to help.

Sometimes cancer specialists recommend radiotherapy to help with pain (see page 40 to 42).

We have more information about other ways of managing cancer pain in our booklet **Managing cancer pain** (see page 94).

Coping with a change in appearance

Depending on your surgery, you may have some small scars (see pages 45 to 48). Or you may have bigger areas of skin that look different. Some scars may be more visible, for example if they are on your face.

Changes to your appearance can make you worry about your body image. This is the picture in your mind of how your body looks and works. These worries can make you feel less confident or may affect your relationships and sex life.

Some skin clinics have a make-up specialist who can advise you on the best way to cover up scars. There are also organisations that provide camouflage make-up to cover up scars, for example the British Association of Skin Camouflage (see page 98).

If you are finding things hard, it is important to get support. You may find it helps to talk to your hospital team, someone close to you or a trained counsellor. There are also other organisations that may be able to help (see page 98).

We have more information that might help you in our booklets **Your feelings after cancer treatment, Body image and cancer** and **Talking about cancer** (see page 94).

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 the body.

The lymph nodes help 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 collects in the tissues under the 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** (see page 94). They both explain this condition in more detail.

Effects on your sex life

Some people find the cancer has no effect on their sex life. Others find the melanoma or its treatment have physical effects that make them feel less interested in sex, such as:

- tiredness
- feeling self-conscious about any changes in the way they look.

You can talk to your team about any worries you have.

We have more information about your relationships and sex life that you might find helpful. Visit **macmillan.org.uk/information-and-support/coping/relationships**

Complementary therapies

Some people find complementary therapies can help improve their quality of life and well-being. Some complementary therapies may help people cope with symptoms or side effects.

Some hospices and hospitals offer complementary therapies along with conventional care. These may include:

- massage
- relaxation
- visualisation
- guided imagery techniques.

Always let your cancer specialist know if you are thinking of trying complementary therapies. You should also tell them about any supplements or herbal medicines. Some of these may interact with chemotherapy or targeted therapy.

We have more information about cancer and complementary therapies in our booklet **Cancer and complementary therapies** (see page 94).

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

Your feelings

It is natural to have a mix of emotions when coping with advanced cancer. These feelings can occur at different times, and they may be different from day to day. Most people find that over time their feelings become easier to cope with.

Uncertainty

Coping with advanced cancer can mean living with uncertainty. This uncertainty may be about how well treatment will work, how will you feel, or practical things like money and work. You may worry about the effect of the cancer on the people you love, and how you will all cope as it develops. These are natural concerns, and there are lots of people who can help support you with these.

Uncertainty is one of the hardest things to deal with for you and your family and friends. You may feel irritable, angry and frightened. It is hard to make plans when you do not 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.

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

Fear

Many people with advanced cancer feel frightened. You may have times when you feel afraid of the illness and its symptoms, or the treatment and its side effects. You may worry about the effect it will have on your family. People often worry about the future or about dying. Talking to your healthcare team can help. They can explain how they can help. For example, they can give you medicines to manage side effects, or tell you what other support is available.

Anger

You may feel angry about feeling unwell, going through treatment and having to cope with the side effects.

You may feel angry if the cancer has affected your work or your relationships. Or you might feel frustrated if it has affected plans you have made. It can help to talk about how you feel. You could talk to a family member or friend. You may also find talking to a counsellor could help.

> ‘It’s ok to cry and feel angry, scared, worried, anxious. It is a very tough time. Take little steps – take each day as it comes.’
>
> **Sharon**

Avoidance

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

Occasionally, this avoidance can be extreme. Some people may not believe they have advanced cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it is 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 hard to cope with, and they may need support too. Try to let them know how this makes you feel. Explain that talking openly with them about your illness will help you.

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 is impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors do not 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 do not have enough support. Family or friends may live far away or have other commitments. 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** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It is normal to have times when you want to be left alone to sort out your feelings. But if you find you are avoiding people a lot of the time, 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 one. For example, a person might be frightened but express their fear by being short-tempered and irritable with the people around them. Talking about our feelings can help us understand our behaviour and what is causing 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 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 chance to talk about your feelings if you want to.

If you need more help

These feelings can be hard to cope with, and sometimes people need more help. This happens to lots of people and does not mean you are not coping.

If you feel anxious, panicky or sad lots of the time, talk to your doctor or nurse. They can talk to you about your concerns and refer you to a counsellor. They may also suggest some medicine to help you cope.

> ‘No individual journey through the cancer maze is ever the same. However, I have found that it can be somewhat possible to live like a typical 20-something. Perhaps I have needed to alter the parameters of what is considered “normal” as time has gone on, but I am living. I hope there are other people like me doing the same.’
>
> **Jolene**

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 might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is 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. Visit **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 (see page 94).

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 in our booklet **Looking after someone with cancer** (see page 94).

Talking to children and grandchildren

It can be very hard 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. It is natural to want to protect them. But 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 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 hard thing to do, and you may need help and support.

Our booklet **Preparing a child for loss** has more information that can help support you (see page 94).

Teenagers

Teenagers may find it particularly hard, because they are going through a lot of emotional changes themselves. They may need to take on more responsibilities at 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. This could be 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 (see page 94). There is also a video on our website that may help. Visit **macmillan.org.uk/talkingtochildren**

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.
- If you feel you are not coping well, or need more support, talk to your doctor or nurse.

FINANCIAL SUPPORT AND WORK

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Visit **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £380. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Our booklet **Help with the cost of cancer** has lots more information (see page 94).

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 94). Our Online Community forum **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisors and financial guides. You can speak to one 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 (see pages 103 to 104).

> ‘I phoned a Macmillan welfare rights advisor. He had a chat to me about certain benefits I could be entitled to. He advised how to cut back on certain bills, and that he could help me to arrange payment plans on some of my bills.’
>
> **Sharon**

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected. It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 94).

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

Employment rights

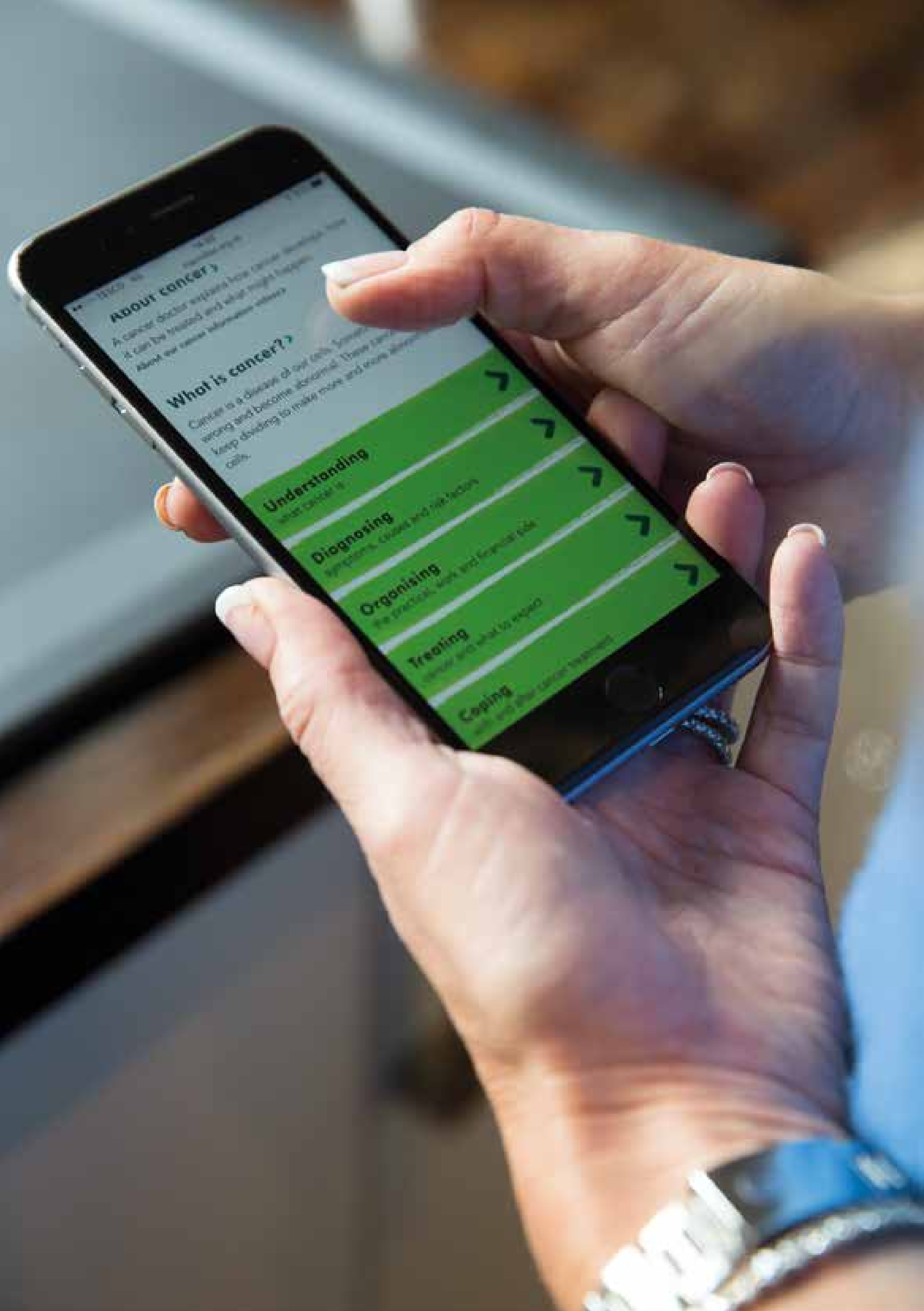
If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 94).

> ‘Time passed and I began a job. Before that, recovery and travelling were too much. Working was a huge achievement – a mini fist-bump to myself!’
>
> **Jolene**


About cancer ›
What is cancer? ›
Understanding
what cancer is
Diagnosing
symptoms, causes and risk factors
Organising
the practical, work and financial side
Treating
cancer and what to expect
Coping
with and after cancer treatment

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**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **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** 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**

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**

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.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit **publications.macmillan.org.uk** and search 'book reviews'.

> '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** 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**

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 (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

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

Melanoma support organisations

The British Association of Dermatologists (BAD)

Tel 020 7383 0266
Email admin@bad.org.uk
www.bad.org.uk
Has information leaflets you can download from the website. Also has another website offering emotional support for people with different skin conditions – visit **skinsupport.org.uk**

The British Association of Skin Camouflage

Tel 0125 470 3107
www.skin-camouflage.net
Shows people how to use make-up as skin camouflage.

Changing Faces

Tel 0300 012 0275
(Mon to Fri, 10am to 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 specialists in locations across the UK. To find your local centre, visit **changingfaces.org.uk/skin-camouflage/clinic-venues**

Melanoma UK

Tel 0808 171 2455
Offers a range of information and support to anyone with melanoma.

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 ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland
Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK
Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
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
(Mon to Fri, 9am to 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.

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 Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org

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

Penny Brohn UK

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
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
(Daily, 8am to 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, benefits advice and an online 'Ask the nurse' service.

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 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Scottish Cancer Registry

Tel 013 1275 7050
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

General health information

Health and Social Care in Northern Ireland

www.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 Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm, Sat and Sun, 9am to 5pm)
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 01455 883 300
Email bacp@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.

Emotional and mental health support

Mind

Helpline 0300 123 3393
(Mon to Fri, 9am to 6pm)
Text 86463
Email info@mind.org.uk
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

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 2450
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
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. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
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 in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm,
Sat, 9am to 12.30pm)
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
(Mon to Fri, 9am to 5pm)
Textphone 028 9031 1092
nidirect.gov.uk/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.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline 0800 022 4250
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
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.

Law Centres Network

www.lawcentres.org.uk
Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland). You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.gov.uk/authorities
Macmillan Benefits Advice Service (Northern Ireland)
Tel 0300 1233 233

Money Advice Scotland

Tel 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel 03448 920 902
(Daily, 8.30am to 5pm)
Textphone 18001 03448 920 900
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity
Tel 080 0138 1111
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

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.

Equipment and advice on living with a disability

British Red Cross
Tel 0344 871 11 11
Textphone 020 7562 2050
Email information@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.

Disabled Living Foundation (DLF)
Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Disability Rights UK
Tel 0207 250 8181
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email enquiries@disabilityrightsuk.org
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
(Mon to Fri, 8am to 7pm, Sat, 9am to 1pm)
Textphone 0300 037 0100
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.

Scope

Helpline 0808 800 3333
(Mon to Fri, 8am to 8pm)
Textphone Use Type Talk by dialling 18001 from a textphone followed by 0808 800 3333.
Email helpline@scope.org.uk
www.scope.org.uk

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for young people

CLIC Sargent

Tel 0300 330 0803
(Mon to Fri, 8am to 6pm)
www.clicsargent.org.uk

Provides clinical, practical, financial and emotional support to children with cancer in the UK.

Teenage Cancer Trust

Tel 0207 612 0370
(Mon to Fri, 9am to 5.30pm)
Email
hello@teenagecancertrust.org
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.

Youth Access

Tel 020 8772 9900
Email
admin@youthaccess.org.uk
www.youthaccess.org.uk

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

Support for older people

Age UK

Helpline 0800 678 1602
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm)
Email helpline@lgbt.foundation
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.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@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 and Tue, 10am to 4pm)
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.

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline 0303 123 9999
(Mon to Fri, 8am to 8pm, Sat, 9am to 1pm)
Email helpline@rnib.org.uk
www.rnib.org.uk
Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

Action on Hearing Loss

Helpline 0808 808 0123
(Mon to Fri, 9am to 5pm)
Textphone 0808 808 9000
SMS 07800 000 360
Email informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk
Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Advanced cancer and end-of-life care

Hospice UK

Tel 020 7520 8200
Email info@hospiceuk.org
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline 0800 090 2309
(Mon to Fri, 8am to 6pm, Sat, 11am to 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.

The Natural Death Centre

Helpline 01962 712 690
Email rosie@naturaldeath.org.uk
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Childhood Bereavement Network

Tel 020 7843 6309
Email cbn@ncb.org.uk
www.childhoodbereavementnetwork.org.uk
A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Cruse Bereavement Care

Helpline 0808 808 1677
(Mon, 9.30am to 5pm, Tue to Thu, 9.30am to 8pm, Fri, 9.30am to 5pm)
Email info@cruse.org.uk
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Hope Again

Helpline 0808 808 1677
(Mon to Fri, 9.30am to 5pm)
Email
hopeagain@cruse.org.uk
www.hopeagain.org.uk
Designed for young people by young people, Hope Again is part of Cruse Bereavement Care. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

Widowed and Young (WAY)

www.widowedandyoung.org.uk
A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

Winston's Wish

Helpline 08088 020 021
(Mon to Fri, 9am to 5pm)
Email info@winstonswish.org
www.winstonswish.org.uk
Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

YOUR NOTES AND QUESTIONS

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 Dr James Larkin, Senior Medical Editor.

With thanks to: Dr Veronique Bataille, Consultant Dermatologist; Donna Begg, Macmillan Clinical Nurse Specialist, Skin Oncology; Mr Amer Durrani, Consultant Plastic and Reconstructive Surgeon; Dr Louise Fearfield, Consultant Dermatologist; Dr Maria Marples, Consultant Medical Oncologist; Helen Moorey, Lead Skin Cancer Nurse; Mr David Mowatt, Consultant Plastic and Reconstructive Surgeon and Dr Andrew Sykes, Consultant Clinical Oncologist.

Thanks also to 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

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Dummer, et al. Cutaneous melanoma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. Annals of oncology. 2015. Volume 26, issue suppl_5. Pages v126–v132.
National Institute for Health and Care Excellence. Melanoma: assessment and management. 2015.

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.

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

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

Valid from

Expiry date

Issue no

Security number

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.

Registered with FUNDRAISING REGULATOR

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

27530

This booklet is about melanoma that has spread to another part of the body (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 talks about the signs and symptoms of advanced melanoma. It explains how it is diagnosed and how it may be treated. It also explains the different ways of managing symptoms, and coping with advanced melanoma. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am 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.

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

MAC12179_E04_N. Next planned review 2021.
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.