WE ARE MACMILLAN. CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING MELANOMA THAT HAS COME BACK IN THE SAME AREA

This booklet is about melanoma that has come back in the same area. It is part of a series of booklets on melanoma. The other booklets in the series are:

- **Understanding melanoma and treatment with surgery**
- **Understanding melanoma – lymph node assessment and treatment**
- **Understanding advanced melanoma**

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

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

About this booklet

This booklet is about treatments that may be used if a melanoma comes back in the same area.

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 with surgery. However, sometimes a melanoma comes back very close to the original site. There are different treatments for melanoma that comes back in the same area.

We hope this booklet answers your questions and helps you deal with some of your feelings.

There are quotes in this booklet from people affected by melanoma. Some are from the website **healthtalk.org** and others are from people who have chosen to share their stories with us (some names have been changed).

We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

At the end of this booklet are some useful addresses and websites (see pages 59–63). There's also space for you to write down any notes or questions for your doctor or nurse (see page 64).

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

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

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. You can find more information at **macmillan.org.uk/cancerregistry**. To find details about the cancer registry in your area, see pages 61–62.

Contents

WHY CANCERS COME BACK

Why do cancers come back?

Sometimes cancer can come back. This can happen because tiny cancer cells, which can't be seen with the naked eye or on scans, can sometimes be left behind after cancer treatment. Unfortunately, no treatment is guaranteed to be 100% effective.

Over time, these cancer cells can begin to divide again and form a tumour.

Most melanomas are successfully treated with surgery. Sometimes melanoma cells can remain, and in some people the melanoma might come back – sometimes many years later.

If melanoma comes back in the same area of the body, it is known as a **local recurrence** or **recurrent melanoma**. Occasionally, melanomas come back as 'clusters' of melanomas. The clusters are in the same area as the original melanoma, but a bit further away. Doctors sometimes call these satellite or in-transit lesions.

Sometimes melanoma cells spread to a different part of the body, where they grow into a new cancer called a **secondary cancer** or **metastasis**. When melanoma comes back in a different part of the body, it is known as advanced cancer.

This information is about melanoma that has come back in the same area. We have separate information about advanced melanoma that we can send you. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order our booklet **Understanding advanced melanoma**. We also have information about advanced melanoma on our website (**macmillan.org.uk**).

TREATING MELANOMA THAT HAS COME BACK IN THE SAME AREA

Treatment overview

Surgery is the main treatment for a melanoma that comes back in the same area (see pages 14–17). You may have surgery to remove a single recurrence or more than one recurrence.

If you have a lot of recurrences, it may be difficult to remove them all with surgery. In this case, your specialist may suggest that you have treatment with a targeted therapy (see pages 18–19) or sometimes laser therapy (see page 20).

If the recurrences are confined to a limb, you may be advised to have chemotherapy directly into that limb (see pages 21–22). These treatments are carried out in specialist centres.

Sometimes, doctors use radiotherapy to treat a recurrent melanoma (see pages 23–25). It may be used if the melanoma is too big to remove with surgery or if other treatments aren't suitable. Melanomas are not very sensitive to radiotherapy, but it may help shrink a recurrence that is large and causing pain.

Planning your treatment

The multidisciplinary team (MDT) who planned your original surgery (wide local excision) will also be involved in planning treatment of any recurrence. The MDT may include:

- dermatologists (doctors who specialise in skin conditions)
- skin cancer nurse specialists
- plastic surgeons
- oncologists (doctors who specialise in treating cancer).

They will meet to discuss the treatment plan they feel is best for you.

The MDT will take a number of factors into account when advising you about treatment. They will consider your general health, the size of the recurrence and whether it has begun to spread.

If two treatments are equally effective, your doctors may offer you a choice. Sometimes people find it hard to make a decision. If you are asked to choose between treatments, make sure you have enough information about the different options, what is involved and the possible side effects. This will help you decide on the right treatment for you.

You may find it helpful to read our booklet **Making treatment decisions**. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Giving your consent

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

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

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment.

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

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

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

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.

Surgery

If your melanoma comes back at the original site or very close to it, you may be able to have surgery to remove it. This is called a local excision.

You will probably have the surgery under a local anaesthetic in the day surgery unit. Some people may have a general anaesthetic, depending on how much tissue needs to be removed.

The wound can usually be stitched together. Your specialist nurse will talk to you about how to look after the wound area. It will look red and sore at first, but this will gradually get better. Your stitches will be removed 5 to 14 days later, depending on where the melanoma was. You will have a scar, which is usually small and becomes less noticeable with time. Sometimes, the wound may be too big to stitch together. In this case, you may need to have a skin graft or a skin flap to mend the wound.

Skin grafts

A skin graft is a layer of skin taken from another part of the body and placed over the area where the melanoma was removed. The place where the skin is taken from is known as the donor site. The place where it is moved to is called the grafted area. The amount of skin that is taken depends on the size of the area to be covered. Your doctor or specialist nurse will tell you more about this.

The donor site

You will have a dressing on the donor site to protect it from infection. How long the site takes to heal will depend on how much skin was removed. If skin was taken from the thigh, buttock or upper arm, it may take up to two weeks to heal. If it was taken from the neck, behind the ears or the inner side of the upper arm, it may only take about five days to heal. The donor site can often feel more uncomfortable than the grafted area. You may need to take regular painkillers for a while.

The grafted area

The grafted area may be secured with stitches. You will have a dressing over it, which will be left in place while the graft heals. The skin graft will connect with the blood supply in the area. This usually takes five to seven days. The area will look red and swollen to begin with, but eventually it will heal and the redness will fade.

After skin graft surgery

After a skin graft, you can usually go home on the same day. Some people need a short stay in hospital depending on where the graft is and how big it is.

Try not to do too much during the first couple of weeks after surgery. You will need to allow the graft to heal properly. The grafted area will be quite fragile. It is important not to put pressure on it, or rub or brush against it. Some people may need to take some time off work until it has healed. If you have young children, you may need some extra help at home until you feel able to do the things you normally do.

Your stitches will be removed 5 to 14 days after your operation. Some people may have stitches that dissolve and don't need to be removed.

Both the grafted and donor areas will develop scars. These should gradually become less noticeable. There will also be some difference between the grafted skin and the skin surrounding it. This will lessen over time. Your hospital team can tell you more about what to expect.

Skin flaps

A skin flap is a slightly thicker layer of skin than a graft. It is taken from an area very close to where the melanoma was. The flap is cut away but left partially connected, so it still has a blood supply. It is moved over the wound and stitched in place. If you have a skin flap, you may need to stay in hospital for a few days.

Skin flap surgery is very specialised. It is usually done by a plastic surgeon. You may have to travel to a different hospital to have it. If you need a skin flap, your doctor will be able to tell you more about it.

> 'With scars, it obviously takes time. But it's something to embrace and be proud of, because it's part of who you are now. And it shows how far you've come.'
>
> **Olivia**

Coping with a change in your appearance

Depending on your surgery, you may have some small scars. Or you may have larger areas of skin that look different. Some scars may be more visible, for example if they are on your face.

People cope with changes in appearance differently. Some people may not be upset by them. Others find these changes harder to cope with or feel self-conscious. It isn't always related to the size or visibility of the change. A small, hidden scar can still affect a person's confidence. Everyone is different.

Give yourself time to get used to the changes. You may find you feel better about them after a while. Scars will also become less noticeable as time goes on.

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 (see page 59).

If you are finding things difficult, it's important to get support. You may find it helps to talk to your hospital team, someone close to you or a trained counsellor. The organisations listed at the end of this booklet can help (see pages 59–63).

You may find it helpful to read our booklet **Body image and cancer.** Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Targeted therapies

Targeted therapies are drugs that target specific proteins (receptors) on the surface of cells. They may be called biological therapies. They are sometimes used to treat melanoma that cannot be removed with an operation.

Some targeted therapy drugs help the body’s immune system to fight cancer. This is known as immunotherapy.

Two immunotherapy drugs that are sometimes used to treat melanoma are:

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

They target a protein called a PD-1 receptor. This protein switches off T cells. T cells are part of the body’s immune system and help the immune system to fight cancer. The drugs attach to the PD-1 receptor so the T cells can’t be switched off. This keeps the T cells active and may help shrink a tumour or stop it growing.

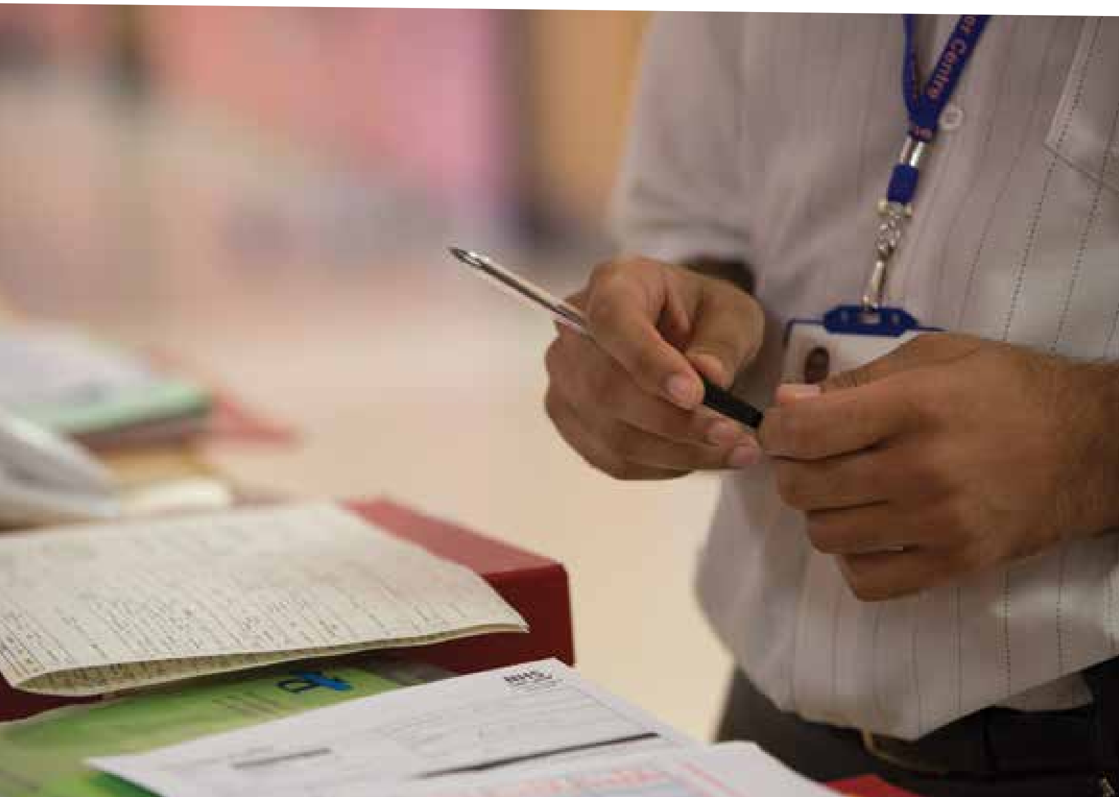
These drugs are given as a drip (infusion) into a vein. Possible side effects include tiredness (fatigue), diarrhoea, sickness (nausea), joint and muscle pain, and a skin rash.

Your doctor or specialist nurse will give you more information about these treatments if they are suitable for you. We can also send you more information.

T-VEC (Imlygic®) is a newer immunotherapy treatment that may sometimes be used to treat melanoma that can’t be removed with surgery. The drug is injected directly into the melanoma. Possible side effects include headaches, tumour pain, flu-like symptoms and tiredness (fatigue). Your doctor or specialist nurse will give you more information.

T-VEC may only be available in some situations. Your cancer doctor can tell you if it is appropriate for you. If a drug isn't routinely available on the NHS, there may be other ways you can get access to it. Your cancer doctor can give you advice.

We can send you more information on what to do if a treatment isn't available on the NHS. Contact our cancer support specialists free on **0808 808 00 00**, Monday to Friday, 9am to 8pm. Or you can order information online at **be.macmillan.org.uk**



Laser therapy

A treatment called carbon dioxide (CO_2) laser therapy can be used to treat small melanomas that come back in the same area. It involves directing a high-intensity beam of light at the affected areas of skin to destroy the melanoma.

You can have this treatment as an outpatient. You can receive 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, but this can be relieved with mild painkillers. The area may be covered with a dressing to protect it afterwards.

Chemotherapy into an arm or leg

You may be given chemotherapy directly into an arm or leg (limb) to treat clusters of melanomas that have come back in the same limb. These clusters of melanomas are called satellite lesions or in-transit lesions (see page 6). This treatment is only given if the melanoma hasn't spread anywhere else in the body.

There are two ways of giving chemotherapy into a limb:

- isolated limb perfusion
- isolated limb infusion.

Some targeted therapies can also be given in the same way.

These treatments are only carried out in some specialist centres in the UK. Your doctor or specialist nurse will give you more information about the drugs you will have.

Isolated limb perfusion (ILP)

This involves giving high doses of chemotherapy or targeted therapy drugs directly into the affected limb. The limb is isolated using a tight band (tourniquet). This means the drugs don't go to other areas of your body. You are therefore unlikely to get the side effects the drugs usually cause when they circulate around the body.

You will be given a general anaesthetic. During the procedure, the surgeon temporarily disconnects the blood flow between your affected limb and the rest of your body. The blood is circulated through an external pump where the drugs can be added, before going back into your limb. Oxygen will also be added to your blood as it circulates through the pump. This is because your limb still needs to get oxygen during the treatment. Your blood will be heated, as some research shows that this improves the results of the treatment.

After the procedure, the blood flow from your limb is reconnected to the rest of your body and the tourniquet is removed. The blood supply to your limb goes back to normal.

Your hospital team will tell you how long the treatment will take. You will usually have to stay in hospital for 3 to 7 days after the procedure.

The main side effects of this treatment are swelling, redness and occasionally blistering of the skin on the affected limb.

Isolated limb infusion (ILI)

This is similar to isolated limb perfusion and may be used as an alternative. Unlike ILP, the blood doesn’t circulate through a pump and no oxygen is added. This makes the treatment shorter. The chemotherapy or targeted therapy drugs will be added in a similar way and will circulate in your limb for about 20 to 25 minutes.

Your doctors will be able to tell you more about isolated limb infusion if this is a suitable treatment for you. We have more information about chemotherapy into a limb that we can send you – call us on **0808 808 00 00**.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is usually given as a series of short, daily treatments in the radiotherapy department, using equipment similar to a large x-ray machine. The photo on page 25 shows someone having radiotherapy.

Radiotherapy is sometimes used to treat recurrent melanomas that can't be removed with surgery or aren't suitable for other treatments. It may help to shrink large recurrences that are causing discomfort or pain. Your specialist will tell you if radiotherapy is suitable for you.

External radiotherapy doesn't make you radioactive. It's perfectly safe for you to be with other people, including children, after your treatment.

How radiotherapy is given

The treatment is normally given in the hospital radiotherapy department as a series of short, daily sessions Monday to Friday, with a rest at the weekend. Each treatment takes 10 to 15 minutes. Your doctor will discuss your treatment plan and the possible side effects with you.

Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it's as effective as possible. It's planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you'll be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment, you will be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Side effects

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

Other side effects will depend on the area being treated and how much radiotherapy you are having. Your nurse or radiographer will discuss these with you so that you know what to expect. Tell them about any side effects you have, as there are often things that can help.

Most of the side effects of radiotherapy are temporary and will gradually go away when your treatment is over.

You can read more about radiotherapy and possible side effects in our booklet **Understanding radiotherapy**. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Someone having radiotherapy

Electrochemotherapy

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

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

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

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

Side effects of electrochemotherapy

The side effects are usually mild.

Some people get pain in the area where the electrode touches 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 can be uncomfortable. Tell your doctor if this happens. Slightly changing the way the treatment is given can help. The contractions will stop after the treatment is finished.

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

AFTER TREATMENT

Follow-up

After your treatment, you will have regular follow-up appointments. Your specialist will let you know how often these will be.

During these appointments, your specialists will examine any areas that have been treated for melanoma. They will also examine any existing or new moles, and your lymph nodes.

Sometimes, a melanoma that has previously come back in the same area can spread to other parts of the body. This is known as a secondary cancer (metastasis). If a melanoma does spread to other parts of the body, further treatment can be given.

You can read about this in our booklet **Understanding advanced melanoma**. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

What to look out for

You will need to continue checking your skin and lymph nodes after treatment. Follow your specialist's advice about what to look and feel for. Make sure you examine yourself at least once a month.

The ABCDE checklist can help you remember what to look for:

- **A – asymmetry** – most melanomas have an irregular shape and are not symmetrical.
- **B – border** – melanomas are more likely to have a blurred or irregular border with jagged edges.
- **C – colour** – melanomas tend to have more than one colour, such as brown, black, red and white.
- **D – diameter** (width) – melanomas are usually wider than 6mm.
- **E – evolving** (changing) – melanomas will change over time, for example in size or colour.

If you notice anything that concerns you, let your specialist team at the hospital know.

For more information about the ABCDE symptoms, visit **macmillan.org.uk/melanomasymptoms** There is a video that shows photographs of the ABCDE symptoms. There is also information in our booklet **Understanding melanoma and treatment with surgery.**

After treatment for melanoma

Many people with melanoma find they can get back to normal quite easily. For others, it may be more complicated. In time and with the right support, people often find they can adjust to any changes they need to make to their lives.

Skin care in the sun

After treatment for melanoma, it is important to protect your skin from the sun. This doesn't mean that you can no longer enjoy sunshine or have holidays in sunny countries. But you will need to be careful. You must make sure your skin does not burn. Over time, this will become part of your normal routine.

There are a number of things you can do to protect your skin:

- Stay out of the sun or strong sunlight during the hottest part of the day. This is usually between 11am and 3pm.
- Wear clothing made of cotton or natural fibres which have a close weave. These will give you more protection against the sun.
- Keep your arms and legs covered by wearing long-sleeved tops and trousers. Wear a wide-brimmed hat to protect your face, neck and ears.
- Always wear sunglasses in strong sunlight.
- Use a high-factor suncream (SPF 30 or above) whenever you are exposed to the sun for a period of time. Follow the instructions on the bottle and re-apply it as recommended. In the autumn, winter and early spring in the UK, there is no need to use above SPF 20 if you only have limited exposure to the sun.

- Choose a suncream that protects against both UVA and UVB radiation. This is known as broad spectrum suncream.
- Don’t use suncream instead of other methods of protecting your skin. Some people think that if they use suncream, they can stay out in the sun for longer. But the best protection is to cover up and to stay out of strong sunlight.
- Never use a sunbed or sunlamp. If it is important for you to look tanned, use fake tan lotions or sprays.
- If you have a skin condition and use a sunbed as part of your treatment, your dermatologist may advise you to stop using the sunbed.

If you aren’t often exposed to the sun, you may want to ask your specialist or GP to check your vitamin D levels. This vitamin is important for general health and can get very low in people who avoid the sun. You may need to take vitamin D supplements.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

Most people feel overwhelmed and experience many different emotions when they are told their melanoma has come back. We talk about some of these here. Partners, family and friends may also have some of the same feelings. You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You will cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that the melanoma has come back. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

> 'Through it all, I've found real comfort in the Macmillan website. It offered not only the facts that I could understand and depend upon, but also the online community where I've been able to chat to other people affected by cancer. It's been a huge support.'
>
> **María Carmen**

Avoidance

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

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

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

Anger

It is common for people to feel angry about having melanoma, especially when it comes back again. Anger can hide other feelings, such as fear or sadness. You may direct your anger at the people closest to you, or at your doctors and nurses.

Your relatives and friends may sometimes think your anger is directed at them, when it is really directed at your illness. It may help to tell them this.

Guilt and blame

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

Feeling alone

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups**

You can also talk to other people going through the same thing on our online community at **macmillan.org.uk/community**

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

If you need more help

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

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

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail and has suggestions for coping with them. We also have a booklet called **Talking about cancer**. You can order free copies by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

> 'Suddenly something is happening to you that you can't control, and that's a horrible feeling. I think that you have to build up a team around you that are sort of like 'Team Karen'. And I think if you can build that up and feel as if all those people are rooting for you, that makes you feel as if you've got a little bit of the control back.'
>
> **Karen**

If you are a relative or friend

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

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

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

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

You may want to read our booklet **Talking with someone who has cancer**. If you're looking after someone with cancer, our booklet **Looking after someone with cancer** may help. It's based on carers' experiences and has lots of practical tips and information. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order free copies.

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers when an adult has cancer** includes discussion about sensitive topics. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy. There's also a video on our website that may help, at **macmillan.org.uk/talkingtochildren**

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.

FINANCIAL SUPPORT AND WORK

Your finances

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

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

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

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance (DLA)** in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

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

More information about benefits

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Scotland and Wales) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 63) or Citizens Advice (see pages 62–63). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Our booklet **Help with the cost of cancer** has more detailed information. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 62–63.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order free copies.

Work

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

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible.

It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

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

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

You may find our booklets **Work and cancer, Working while caring for someone with cancer** and **Self-employment and cancer** useful. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order free copies. There's also more information at **macmillan.org.uk/work**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DONATE
DO YOU LOOK AFTER SOMEONE WITH CANCER?
Need to talk? Call us free* > 0808 808 00 00
DESK NOTE BOOK

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

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

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

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

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.

> '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**

Macmillan's My Organiser app

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

Other useful organisations

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

Support with a changed appearance

The British Association of Skin Camouflage

PO Box 3671,
Chester CH1 9QH
Tel 01254 703 107
www.skin-camouflage.net
Shows people how to use make-up as skin camouflage.

Changing Faces

The Squire Centre,
33–37 University Street,
London WC1E 6JN
Tel 0300 0120 275
(Mon–Fri, 10am–4pm)
Email
info@changingfaces.org.uk
www.changingfaces.org.uk
Offers information and support to people who have any sort of disfigurement, and their families. Helps people build effective coping strategies and self-confidence. Has skin camouflage practitioners. Also works with healthcare professionals, schools and employers to promote awareness of disfigurement.

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX
Helpline 0800 783 3339
(Mon–Fri, 9am–1pm)
Email hello@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531
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.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland
Tel 1800 200 700 (Mon–Thu, 9am–7pm, Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie
Offers information, support and care to people affected by cancer. You can talk to a nurse on the phone or online.

Maggie's Centres

The Gatehouse,
10 Dumbarton Road,
Glasgow G11 6PA
Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

Tenovus
Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)
Email info@tenovuscancercare.org.uk
www.tenovus.org.uk

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

Cancer registries

The cancer registry

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

National Cancer Registration Service
Public Health England,
Wellington House,
London SWE1 8UG
Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk

Scottish Cancer Registry
NHS Information Services,
Gyle Square,
1 South Gyle Crescent,
Edinburgh EH12 9EB
Tel 0131 275 7777
Email nss.csd@nhs.net
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)
Public Health Wales NHS Trust,
3rd Floor,
16 Cathedral Road,
Cardiff CF11 9LJ
Tel 02920 373500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Centre for Public Health,
School of Medicine,
Dentistry & Biomedical Sciences,
Queen's University Belfast,
Mulhouse Building,
Grosvenor Road,
Belfast BT12 6DP
Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House,
15 St John's Business Park,
Lutterworth,
Leicestershire LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk

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

UK Council for Psychotherapy (UKCP)

2nd Floor, Edward House,
2 Wakley Street,
London EC1V 7LT
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

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

Financial or legal advice and information

Citizens Advice

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

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **www.citizensadvice.org.uk/resources-and-tools/languages**

Department for Work and Pensions (DWP)

Personal Independence Payment Helpline
0345 850 3322
Textphone 0345 601 6677
Carer's Allowance Unit
0345 608 4321
Textphone 0345 604 5312
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Support for carers

Carers UK

Helpline (England, Scotland, Wales) 0808 808 7777
(Mon–Fri, 10am–4pm)
Tel (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

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

YOUR NOTES AND QUESTIONS

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

The melanoma series of booklets has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. The booklets have been approved by our Senior Medical Editor, Dr James Larkin, Consultant Medical Oncologist, and by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist. We wish to thank the following people for their help in reviewing the melanoma series of booklets: Dr Veronique Bataille, Consultant Dermatologist; Ruth Devlin, Lead Skin Cancer Clinical Nurse Specialist; Ann Irwin, Clinical Nurse Specialist – Skin Cancer; and Professor Barry Powell, Consultant Plastic Surgeon. We'd also like to thank the people affected by cancer who reviewed these booklets, and those who shared their stories.

Sources

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

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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

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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.

FRSB give with confidence

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

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Health & care information you can trust

The Information Standard

Certified Member

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