WE ARE MACMILLAN. CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING MELANOMA

LYMPH NODE ASSESSMENT AND TREATMENT

This booklet is about melanoma that has spread to the lymph nodes, and how it is treated. 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 that has come back in the same area**
- **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 melanoma. It has information about tests to check the lymph nodes close to the melanoma. It also explains the surgery used to remove the lymph nodes if they contain cancer cells.

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

Most melanomas can be removed with surgery. However, a melanoma can sometimes spread to the lymph nodes closest to where it was. Some people need further tests to check the lymph nodes. If they contain cancer cells, you will have surgery to remove them. Surgery to remove lymph nodes is known as a lymph node dissection.

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

We've included quotes from people affected by melanoma, like Ronald, who is on the front cover of this booklet. To share your story, visit **macmillan.org.uk/shareyourstory** Other quotes are from **healthtalk.org** and some names have been changed.

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

ℹ We have more information about melanoma and its treatment that you may find useful. We've highlighted where we mention this information with this icon.

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 and your health is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country. You can find more information at **macmillan.org.uk/cancerregistry**

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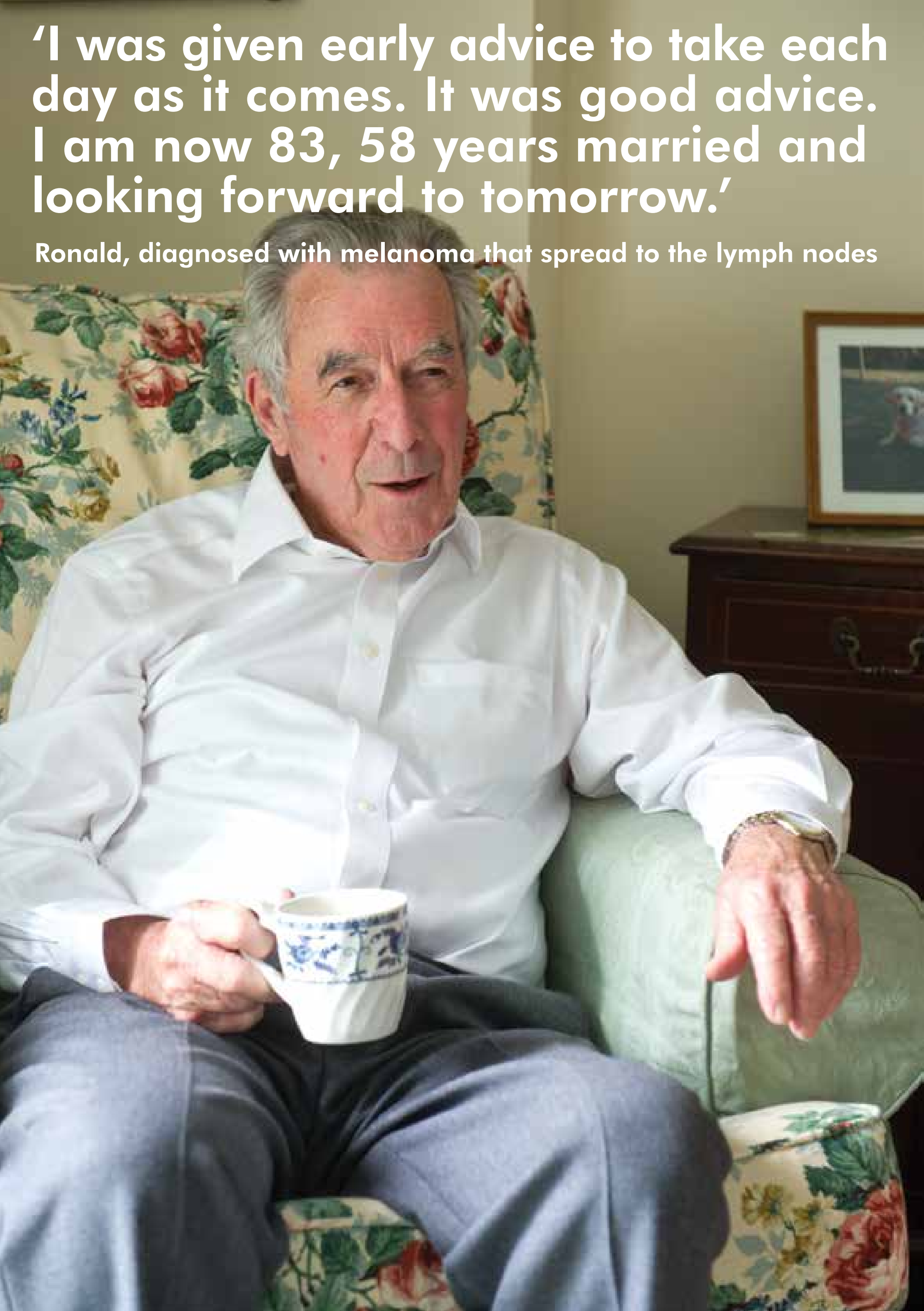
‘I was given early advice to take each day as it comes. It was good advice. I am now 83, 58 years married and looking forward to tomorrow.’

Ronald, diagnosed with melanoma that spread to the lymph nodes



LYMPH NODE ASSESSMENT

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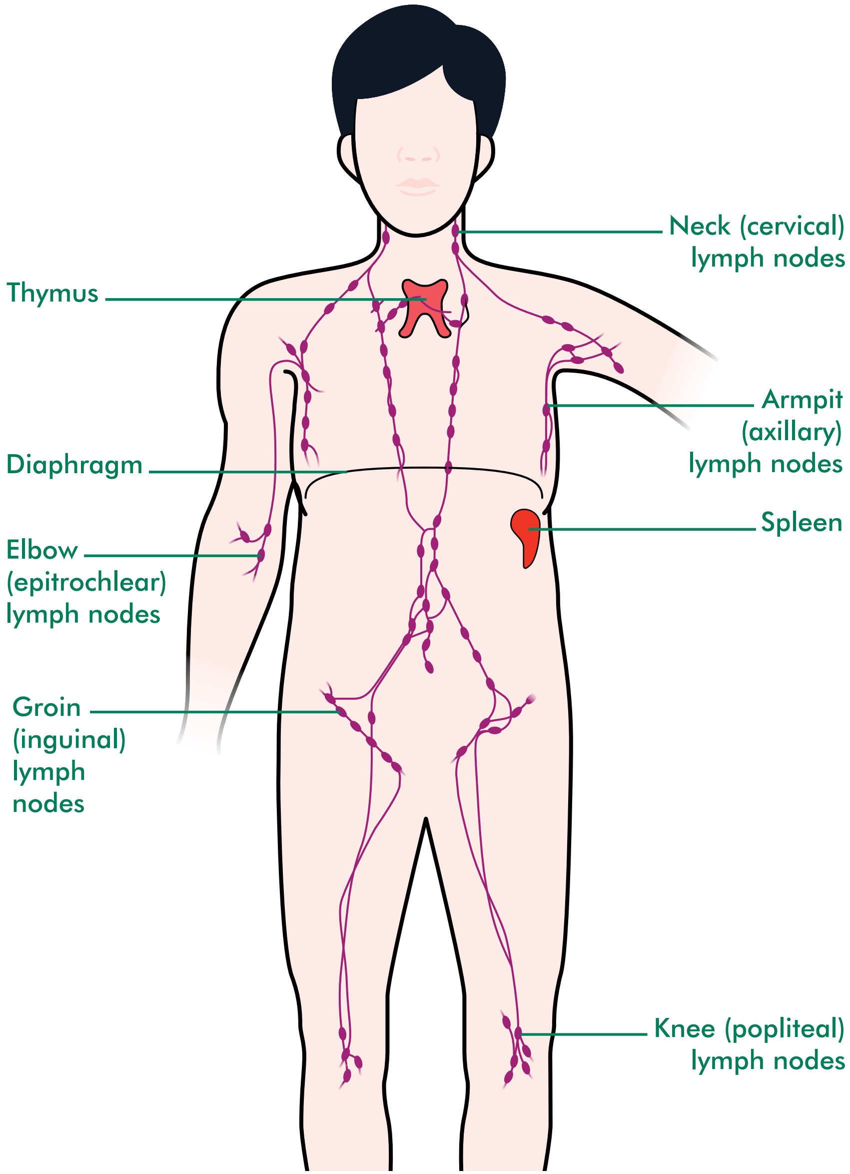
The lymphatic system

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

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection lymph nodes often swell as they fight the infection.

The lymphatic system



Tests to check your lymph nodes

The most common place for melanoma cells to spread is to the lymph nodes closest to the melanoma. Your doctor will examine these nodes to see if they look or feel swollen. For example, if the melanoma is on your leg they will examine the lymph nodes behind your knee and in your groin. If it is on your chest, back or tummy (abdomen), they will check the lymph nodes in your groin and armpits, above the collar bones, and in the neck.

Having swollen lymph nodes doesn't necessarily mean that the melanoma has spread. For example, an infection can also cause lymph nodes to swell.

Your doctor may suggest that you have some tests to check whether any lymph nodes are affected by melanoma. Not everyone needs these tests. Whether you have the tests will depend on the size of the melanoma, and if the lymph nodes look or feel swollen. These tests include:

- A sentinel lymph node biopsy (SLNB). This removes your sentinel lymph nodes. If there is no melanoma found in the sentinel lymph nodes, then it is unlikely that it has spread.
- An ultrasound. This uses sound waves to make up a picture of part of your body.
- A fine needle aspiration (FNA). This withdraws some sample cells from your lymph nodes with a fine needle.

If your tests show that the melanoma has spread to the lymph nodes, you may be advised to have surgery to remove all the lymph nodes in that area (see pages 25–26).

Sentinel lymph node biopsy

You may be offered a test called a sentinel lymph node biopsy (SLNB). This may be done even if the lymph nodes aren’t swollen. It’s a small operation that is done under a general anaesthetic, at the same time as your wide local excision.

You can find out more about wide local excision surgery in our booklet **Understanding melanoma and treatment with surgery**.

The sentinel nodes are the first ones that lymph fluid drains to from your melanoma. If the melanoma has spread to nearby nodes, the sentinel nodes are the ones that are most likely to be affected.

A SLNB can tell your doctors more about your situation and help them plan the best treatment for you. It is not a treatment itself.

If the sentinel nodes don’t contain cancer cells, it is unlikely that other lymph nodes are affected. This means you won’t need to have surgery to remove them.

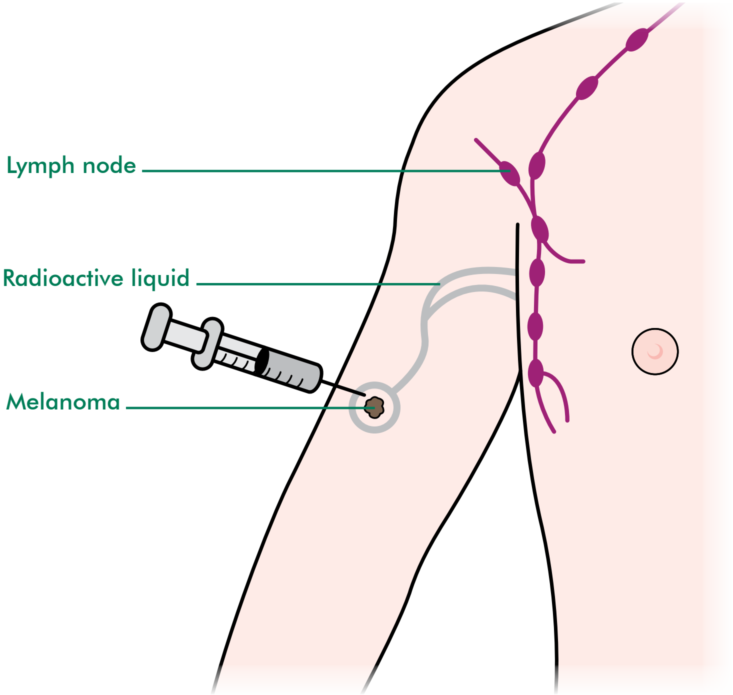
If they do contain cancer cells, your doctor may recommend that you have further surgery to remove all the lymph nodes near to your melanoma (see pages 25–26).

There are still some questions about how worthwhile having an SLNB is. Your doctor will talk to you about whether a SLNB is suitable for you. They will help you decide whether to have the test or not.

Having a sentinel lymph node biopsy

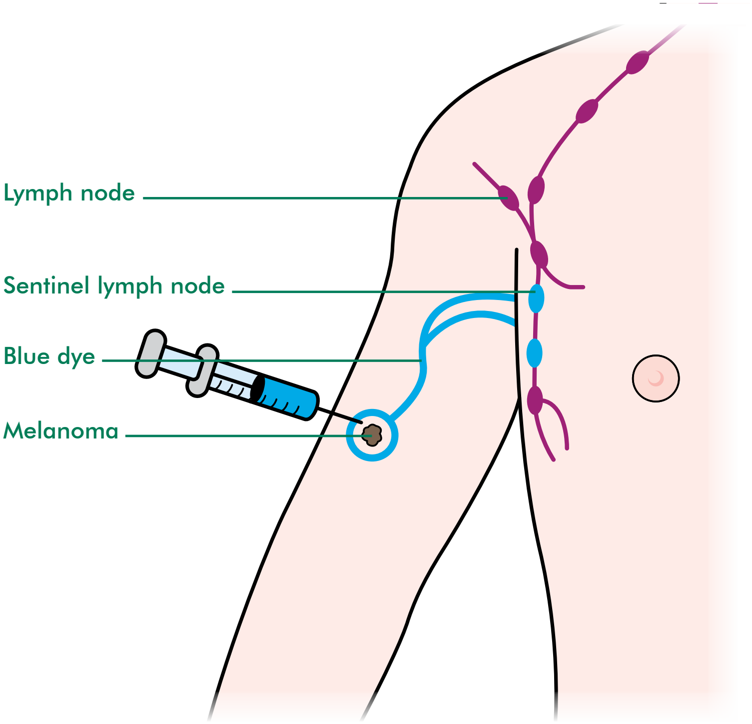
A doctor will inject a tiny amount of a mildly radioactive liquid around the area of your melanoma (see below). This is the same area where you had your excision biopsy. The liquid will make the sentinel lymph nodes mildly radioactive.

Step 1: Radioactive liquid is injected



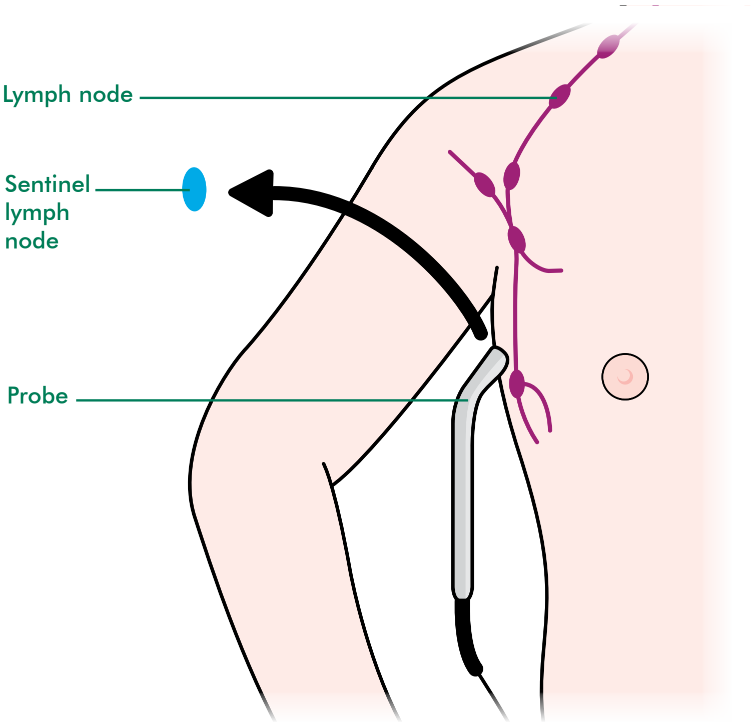
During the wide local excision, the surgeon injects a blue dye into the same area as the radioactive liquid. The dye stains the sentinel lymph nodes blue so the surgeon can see them (see below).

Step 2: Blue dye is injected



The surgeon will use a probe that detects radioactivity to help them find the sentinel lymph nodes. The sentinel nodes are then removed (see below). They are sent to a laboratory and examined under a microscope to see if they contain melanoma cells.

Step 3: The sentinel lymph nodes are removed



Ultrasound and fine needle aspiration (FNA)

Your specialist may suggest that you have an ultrasound to check your lymph nodes. If any of the nodes look abnormal, they may suggest you have a fine needle aspiration.

Ultrasound

Ultrasound uses sound waves to make up a picture of a particular area of the body. It's a painless test and only takes a few minutes.

Once you're in a comfortable position, you'll have a gel spread over the area around the lymph nodes that are being examined. A small device like a microphone, which produces sound waves, is then passed over this area. The echoes are converted into a picture by a computer. If the ultrasound of the lymph nodes is abnormal the doctor will do a fine needle aspiration of the node or nodes.

Fine needle aspiration

A fine needle aspiration is a quick, simple test. The doctor puts a fine needle into the lymph node and withdraws a sample of cells into the syringe. The cells are examined under a microscope to see if they contain any cancer cells.

If they do, you may have other tests to see if the melanoma has spread anywhere else in the body (see pages 14–17). If the melanoma has only spread to nearby lymph nodes, you will be offered surgery to remove all the lymph nodes in that area. Your doctors will discuss this with you. They will also tell you about the benefits and disadvantages of having the nearby lymph nodes removed (see pages 23–24).

Other tests

If your melanoma has spread to the lymph nodes, you may have other tests to see if it has spread elsewhere in the body.

CT (computerised tomography) scan

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

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

You'll probably be able to go home as soon as the scan is over.

Someone having a CT scan

MRI (magnetic resonance imaging) scan

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

Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one.

You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30-90 minutes. You should be able to go home after 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, family or a close friend. Your specialist nurse or one of the organisations listed on pages 59–63 can also provide support.

You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

TREATING MELANOMA THAT HAS SPREAD TO THE LYMPH NODES

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Treatment overview

If your melanoma has spread to nearby lymph nodes, you may be offered further surgery to remove them. This is called a lymph node dissection (see page 25).

Sometimes further treatments are needed (see page 27). This may happen if it hasn't been possible to remove all the lymph nodes, or if your doctor thinks there is a risk that the cancer may come back.

Planning your treatment

The multidisciplinary team (MDT) who planned your wide local excision will also be involved in planning the treatment to remove your lymph nodes. 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 plan of treatment they feel is best for you.

> 'All of the concerns that have arisen from time to time have been addressed by my doctors and nurses. I cannot speak highly enough of them.'
>
> **Ronald**

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.

Benefits and disadvantages of treatment

It is important to be aware of the benefits and disadvantages of surgery to remove your lymph nodes. You should discuss these with your doctors before your treatment. Your doctor or specialist nurse can help you decide whether to have the nodes removed.

Benefits

In many cases, surgery to remove your lymph nodes can help control the local spread and growth of the melanoma. This is especially true if cancer has been found in your lymph nodes because they were swollen and you had an ultrasound or a fine needle aspiration (FNA). However, it is less clear if surgery to remove all the nodes will be helpful if cancer has been found in one lymph node following a sentinel lymph node biopsy (SLNB).

The National Institute for Health and Care Excellence (NICE) has produced guidelines about having lymph nodes removed. They list the possible advantages of a lymph node dissection following a SLNB. The possible advantages of removing the nodes are that:

- it reduces the risk of the cancer coming back in the same part of the body.
- it is safer and less complicated than waiting until cancer develops in the nodes and then removing them
- it means that you may be able to take part in clinical trials of new treatments that aren’t available to people who haven’t had their nodes removed.

Your doctor will be able to discuss these with you.

Disadvantages

Lymph node dissection is a big operation that will leave a scar on your skin. The scar will become less noticeable with time. You may want to discuss with your doctor and nurse what the scar may look like after surgery, and any other possible disadvantages of surgery.

The guidelines about lymph node dissection also list some possible disadvantages of having surgery to remove all the lymph nodes:

- Removing the lymph nodes can sometimes lead to lymphoedema. This is a swelling of an arm, leg or other part of your body, depending on which lymph nodes were removed. There are ways you can help lower your risk of lymphoedema or reduce its severity if it does develop. You can read about lymphoedema on pages 33–37.
- In four out of five people, the cancer will not develop in the remaining nodes. So you may not gain any advantage by having an operation to remove them.
- There is no evidence that people who have the nodes removed live longer than people who don't.

Even if you do have the lymph nodes removed, there is still a risk that the melanoma may come back again. This will depend on the number of the lymph nodes affected by cancer. Your doctor will be able to discuss this with you.

We have more information about making treatment decisions that we can send you.

Surgery to remove the lymph nodes

You will only have this surgery if:

- your specialist thinks your melanoma has spread to nearby lymph nodes
- tests show that they are affected.

You will have your lymph nodes removed under a general anaesthetic. You are likely to be in hospital for three to five days.

The surgery you have and its side effects will depend on the group of lymph nodes being removed. Your specialist doctor or nurse will tell you more about what to expect in your situation. For example, if the melanoma was in your leg, a cut (incision) is made in the groin on the affected side to remove the lymph nodes. If the melanoma was in your arm, the lymph nodes in your armpit on the affected side will be removed. The nodes in your neck will be removed if you had a melanoma anywhere on your face, head or in the neck area.

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

After your operation

After the operation, you may have a small tube in place (a drain) to remove any fluid that builds up around the wound. The drain is connected to a small suction bottle. It will be removed when most of the excess fluid has been drained away. This is usually within a few days. The wound will be covered with a dressing and your stitches or staples will be removed 10 to 14 days later, unless they are the self-dissolving type.

You may also have a drip (infusion) to give you fluids until you are drinking properly again.

You will probably have some discomfort or pain in the area afterwards, but you'll be given regular painkillers until this eases. Occasionally, people continue to have pain after this kind of operation. However, most people can begin to do the things they normally do after a couple of weeks.

After your operation, you may see a physiotherapist who will show you some exercises to help you move normally again.

If your lymph nodes have been removed, there is a risk of developing swelling in an arm or leg or other part of your body, depending on where in the body the lymph nodes were removed. This swelling is called lymphoedema. You can read more about lymphoedema and how to reduce your risk of developing it on pages 33–37.

A small number of people may get a wound infection after this type of surgery. This can be treated with antibiotics.

Some people may get a small collection of fluid around the wound scar. This is known as a seroma. It usually goes away within a few weeks. Sometimes your surgeon may need to drain off the fluid with a needle and syringe.

Further treatment

After you have had your lymph nodes removed, you may not need any further treatment.

Radiotherapy may sometimes be offered after surgery to help reduce the risk of the melanoma coming back. Radiotherapy is treatment with high-energy x-rays.

Radiotherapy to the lymph nodes may sometimes cause long-term side effects, depending on the area being treated. It may also increase your risk of developing lymphoedema (see pages 33–37). If you need radiotherapy, your doctor will give you more information about the treatment and any possible side effects.

If your doctor thinks you will benefit from any drug treatments after your lymph node dissection, they will discuss this with you. These are called adjuvant treatments They are given to reduce the risk of a cancer coming back. You usually have them as part of a research trial. This is because doctors are still trying to find out how effective they are. Your specialist may ask you to think about joining a trial.

We have more information about these treatments in our booklets **Understanding radiotherapy** and **Understanding research trials (clinical trials)**. We can send you free copies – call **0808 808 00 00** or visit **be.macmillan.org.uk**

AFTER TREATMENT

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Follow-up

After your melanoma and lymph nodes have been removed, you will see your skin cancer specialist again for a follow-up appointment.

Your doctor or specialist nurse will examine your scar and the surrounding area. They will also check other areas of your body for moles. Some people may have photographs taken of their skin and some of their moles measured. This is just a way of checking for any changes that may develop. During your appointment, your doctor or specialist nurse may also examine lymph nodes elsewhere in your body.

How often and for how long you will have follow-up appointments will depend on the stage of your melanoma. Your specialist will discuss this with you.

You will be shown how to examine your skin and what to look out for. This will help you spot any signs of the original melanoma coming back, or another melanoma developing, as early as possible.

After you've had a melanoma, you are at more risk of developing another primary melanoma. So you will also be given advice on protecting your skin from the sun (see pages 32–33).

After lymph node removal for melanoma

Many people find getting back to normal after surgery straightforward. For others it may be more complicated. This depends on how the surgery has affected them, or if they are having other treatment. In time, and with the right support, people often find that they can adjust to any changes.

What to look for

It is important to check yourself for any signs of melanoma at least once a month. If another melanoma develops, there is more chance of curing it the earlier it is found. If you have any symptoms that you are worried about, you can contact your hospital doctor or specialist nurse between your follow-up appointments.

You will be asked to check:

- your scar and the surrounding area
- your skin, from head to toe, for any new or changing moles.

The ABCDE checklist in our booklet **Understanding melanoma and treatment with surgery** can also give you an idea of what to look for.

You may also be asked to check other lymph nodes after your treatment. The British Association of Dermatologists (see page 59) produce a leaflet with advice about how to check your lymph nodes. You can download a copy from their website – visit **bad.org.uk**

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 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.

Lymphoedema

Lymphoedema is a swelling of an arm, leg or, sometimes, another part of the body. It sometimes happens after you have had surgery or radiotherapy to lymph nodes. This is because taking the lymph nodes away or treating them with radiotherapy can sometimes block the normal flow of lymph fluid. If this happens, fluid collects in the tissues under your skin and causes swelling.

Lymphoedema develops on the same side that your lymph nodes were removed from. For example, if you have lymph nodes removed from your right groin area, you may develop lymphoedema in your right leg. Or if you have lymph nodes removed from your right armpit, you may get lymphoedema in your right arm.

Lymphoedema can develop weeks, months, or even years after treatment.

Reducing the risk of lymphoedema

There are things you can do to reduce your chances of developing lymphoedema. Here are some tips:

Protect the skin on your limb

- Keep your skin clean and dry. Use soap-free cleansers that don't dry your skin.
- Moisturise gently every day with unperfumed cream or oil to help your skin stay in good condition.
- Don't use waxing or sugaring to remove unwanted hair. Hair removal creams can be harsh on the skin so be careful and try a small test patch before using them on larger areas.
- Wear long trousers and long sleeves when gardening to avoid being scratched.
- Protect your skin in the sun and don't get sunburnt.
- If you travel to an area where there's a high risk of being bitten or stung by insects, wear long-sleeved clothes and apply an insect repellent that can be used on sensitive skin.

Look after your feet and legs (if your groin nodes have been removed)

- Wear well-fitting footwear.
- Wash and dry between your toes carefully.
- If you notice any signs of athlete's foot, such as soreness or peeling between the toes, treat it straight away.
- Use nail clippers instead of scissors to cut your nails. There is less risk of accidentally cutting the skin with clippers.

Look after your hands and arms (if the nodes in your armpit have been removed)

- Wear gloves for washing up, DIY, gardening, household tasks and working with animals.
- Use nail clippers to cut your nails. Never push back or cut your cuticles – use cuticle cream instead.
- Wear oven gloves in the kitchen. This should prevent your hands or fingers getting burnt.
- Avoid tight-fitting sleeves. Don’t carry a heavy handbag or shopping with your at-risk arm.
- Don’t try to pick up, push or pull heavy objects such as luggage.

Avoid infection

Preventing infection or getting an infection treated as soon as possible puts less stress on the lymphatic system and can help to prevent lymphoedema.

- Protect your at-risk limb (see page 34).
- If you get a graze or cut, treat it with antiseptic and keep it clean until it heals.
- If you are planning on travelling abroad, ask your GP if it is advisable for you to carry antibiotics with you. This is just in case you develop an infection in your limb.

Contact your GP straight away if you notice any swelling, redness, pain or heat in your at-risk limb. These symptoms may be due to cellulitis. This is an infection of the deeper layers of skin and underlying tissues. Cellulitis needs to be treated promptly with antibiotics. Your doctor can prescribe these for you.

Exercise

Gentle exercise, such as walking and swimming, helps lymph drainage. But too much exercise can sometimes lead to lymphoedema. Ask your doctor or specialist nurse when you can start exercising and which types of exercise are right for you. Remember to gradually build up your fitness level and take regular breaks between repetitive activities.

Leg positioning (if the lymph nodes in your groin have been removed)

If you have had lymph nodes removed from your groin, there are things you can do to help the lymph fluid drain:

- Raise your feet and legs when you are sitting. Make sure your feet are well-supported on a pillow or cushion if possible.
- Don’t cross your legs when you are sitting.
- If you have to sit with your feet down for a long time, wear support stockings to help lymph drainage.
- If you are going on a long car journey, plan to stop occasionally. Use this time to get out and walk a short distance.
- Try to avoid standing for long periods of time.

Try to keep to a healthy body weight

Being overweight can increase your risk of lymphoedema. If you need to lose weight, talk to your nurse or doctor for advice.

Avoid temperature extremes

Test the temperature of water before bathing, to make sure it is not too hot. Avoid using saunas or hot tubs. You should also try to avoid situations where your at-risk limb is exposed to a rapid temperature change, for example from hot to cold.

Treating lymphoedema

If you notice even mild swelling of your leg, foot, arm or hand, let your doctor know. The earlier treatment begins, the more likely it is to be successful.

You will usually be referred to a lymphoedema specialist. They are based in hospitals, hospices or specialist lymphoedema centres. They can offer advice on self-care and treatments, including special massage techniques, exercises, bandaging and support stockings.

We have a booklet called **Understanding lymphoedema**, which has more information. We can send you a copy.

> ‘A side effect of treatment was lymphoedema. I have to permanently wear a pressure stocking on my right leg. I was told it would reduce the possibility of contracting cellulitus, which it has done to date.’
>
> **Ronald**

Well-being and recovery

After your treatment, you may want to think about making changes to your lifestyle and finding out more about healthy living. There are things you can do to help your body recover. These can also help improve your sense of well-being and lower your risk of getting other illnesses and some cancers.

Eat well and keep to a healthy weight

Eat at least five portions of fresh fruit and vegetables a day. Try to eat more foods that are high in fibre, such as wholemeal, cereal, beans and grains. Eat less red meat, animal fats and salted, pickled and smoked foods. Follow sensible drinking guidelines.

Exercise regularly

Exercise can be an important part of your recovery after treatment. It can improve your well-being and energy levels. It reduces the risk of heart disease, stroke, diabetes and bone thinning (osteoporosis). Talk to your cancer specialist or GP before you start. Start slowly and increase your activity over time.

Stop smoking

If you are a smoker, speak to your doctor or call a stop smoking helpline. They can give you advice and tell you where to find your local stop smoking service.

We can send you booklets about eating well, exercise and stopping smoking. We also have a booklet called **Life after cancer treatment** that may be helpful.

Who can help?

Different people can offer you support in the community. District nurses work closely with GPs and, if needed, they can visit you at home. For example, they may visit you if you have a wound and need the dressings changed. They can also refer you to other community specialists if they think you will benefit from their help. The hospital social worker can give you information about social services and other benefits you may be able to claim while you are ill. The social worker may also be able to help arrange childcare during and after treatment and, if necessary, help with the cost of childminders.

Our cancer support specialists on freephone **0808 808 00 00** can tell you more about services in your area.

‘I have been lucky to have the support of my wife and a wonderful family.’

Ronald

YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It is common to feel overwhelmed by different feelings when you are told that you have melanoma. 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.

You may find it hard to believe it when your doctor tells you that you have melanoma. It is 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. Or you may find you can't think or talk about anything but the melanoma. This is because your mind is trying to process what you're going through.

People can be very anxious 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 is best to talk to your doctor about your individual treatment and what is likely to happen. They may not be able to answer your questions fully, but they can usually talk through any problems with you and give you some guidance.

You may feel angry about your illness. This is a normal reaction. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, and yoga or meditation.

Some people feel guilty or blame themselves or others for the melanoma. 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 the cancer.

> 'I think the most important thing is to be open. I think you've got to be very honest with yourself about how you're feeling.'
>
> **Ellie**

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**

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

If you are a relative or friend

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

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

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

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

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

Talking to children

If you have children or grandchildren, deciding what to tell them 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 when an adult has cancer** includes discussion about sensitive topics. There's also a video on our website that may help, at **macmillan.org.uk/talkingtochildren**

FINANCIAL SUPPORT AND WORK

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Work 51

Financial help and benefits

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

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

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

There are two different types of ESA:

- 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.

From October 2013, a new benefit called Universal Credit is replacing income-related ESA. This 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.

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.

Help for carers

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

More information

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

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

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

Insurance

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

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

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, 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.

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


YOUR FEELINGS
WE ARE MACMILLAN.
CANCER SUPPORT

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About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** 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.

The British Association of Dermatologists (BAD)

Willan House,
4 Fitzroy Square,
London W1T 5HQ
Tel 020 7383 0266
Email info@bad.org.uk
www.bad.org.uk
Offers information leaflets that can be downloaded from the website. Has another website offering emotional support for people with different skin conditions – visit **skinsupport.org.uk**

The British Association of Skin Camouflage

PO Box 3671,
Chester,
Cheshire CH1 9QH
Tel 0125 470 3107
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 012 0275
(Mon–Fri, 10am–4pm)
Email
info@changingfaces.org.uk
www.changingfaces.org.uk
Offers support and information to people who have any sort of disfigurement, and their family and friends. Has skin camouflage practitioners in locations across the UK – to find your local centre, visit **changingfaces.org.uk/skin-camouflage/clinic-venues**

Lymphoedema Support Network

St. Luke's Crypt,
Sydney Street,
London SW3 6NH
Tel 020 7351 4480
Email admin@lsn.org.uk
www.lymphoedema.org

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

Cancer information and support

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
helpline@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
Helpline 1800 200 700
(Mon–Thu, 9am–7pm,
Fri, 9am–5pm)
Email
cancernurseline@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

Provide information about cancer, benefits advice, and emotional or psychological support. Search for your local centre at **maggiescentres.org/our-centres**

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
(Mon–Sun, 8am–8pm)
www.tenovuscancercare.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.

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 financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following 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 **citizensadvice.org.uk/resources-and-tools/languages/**

Department for Work and Pensions (DWP)

Disability Living Allowance Helpline
0345 712 3456
Textphone 0345 722 4433
(Mon–Fri, 8am–6pm)
Personal Independence Payment Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon–Fri, 8am–6pm)
Carer's Allowance Unit
0345 608 4321
Textphone 0345 604 5312
(Mon–Thurs, 8.30am–5pm, Fri, 8.30am–4pm)
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 comprehensive information about social security benefits and public services.

Personal Finance Society – 'Find an Adviser' service

www.thepfs.org/yourmoney/find-an-adviser/
Use the website to find qualified financial advisers in your 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

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

With thanks to: 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.

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

Sources

We've listed a sample of the sources used in this publication below. If you'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

Card number
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Valid from
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Expiry date
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Issue no
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Security number
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Signature

Date / /

Don’t let the taxman keep your money

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

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

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

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

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

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.

Health & care information you can trust
The Information Standard
Certified Member

WE ARE MACMILLAN.
CANCER SUPPORT