

**MACMILLAN**  
CANCER SUPPORT

# GOING HOME FROM HOSPITAL



# About this booklet

This booklet is about the support you can get when you go home from hospital. It is for anyone living with cancer who is leaving hospital. It may also be helpful for family members and friends.

The booklet explains:

- how care and support are arranged for you when you go home
- different health and social care professionals who may be involved in your discharge.

If you need practical help, equipment or nursing care at home, there are people who can help you and your family. It can be difficult to remember all the different professionals you meet in hospital and at home. We have included a table on pages 32 to 34 for you to record names and contact details of the people you may need support from.

We hope it helps you deal with some of the questions or feelings you may have.

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

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

On pages 49 to page 55, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see pages 56 to 57).

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.

## Quotes

In this booklet, we have included quotes from people who have gone home from hospital. These are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or **visit [macmillan.org.uk](https://www.macmillan.org.uk)**

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

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

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



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# How you can prepare

You may have some worries about how you will cope when you leave hospital. But there are different health and social care professionals who can give you support.

Your healthcare team will help make a discharge plan of the support you will get when you leave hospital. A family member, friend or carer can also be involved in your discharge plan, if you are happy with this. Planning is important to make sure you get the support you need. You can talk with your healthcare team about the type of support you think you will need.

You will only go home when the hospital staff are happy that you and any carers will manage.

Our booklet **Looking after someone with cancer** has more information for carers. See page 45 for ways to order this.

# When can I go home?

Everyone needs different support when they go home from hospital. You might decide to stay with family or a friend for a while if you can.

You should only be discharged from hospital when:

- your doctors are happy you are well enough to go home
- you have been given a written discharge plan of the support that you will get (see page 12)
- the support you need has been organised so you can safely manage at home.

The doctors and nurses will tell you when you might be ready to go home. This is known as your expected date of discharge (EDD). This date will be reviewed regularly while you are in hospital. You will be told if it needs to change. This may happen because you are not well enough to go home. Or if there is a delay in organising the help you need. Your hospital will have its own discharge policy and plans for discharging people.



# How are care and support arranged for me?

Tell the nurses or your keyworker as soon as possible if you are worried about how you will manage at home. This helps them plan for your discharge. A keyworker is a healthcare professional. They can often be a nurse. A keyworker is your main contact and source of support during your stay in hospital.

If your stay in hospital was planned, you may have been given information about discharge planning before you went in. If you have a clinic appointment before going into hospital, talk to them about any worries you have about going home.

You might see lots of different health and social care professionals while your discharge is being planned. You might find it difficult to remember who each person is and what they do. If you forget any details, it is always ok to ask for them again. There is a table where you can write down their contact details (see pages 32 to 34).

**'There are no questions that you can't ask a keyworker. Nothing is too big, too small or too silly – that's what they are there for.'**

**Michael, Clinical Nurse Specialist**

## Who arranges my discharge?

Usually a ward nurse or your keyworker makes plans for you to go home. Nurses in the ward work as a team. This means you may not see the same nurse every day. They talk to each other about the support you will need when you go home. They may also involve other health and social care professionals, such as a physiotherapists or occupational therapists (see pages 16 to 23).

When you get home, you may need ongoing care and support from these professionals and different organisations. If you do, a liaison nurse, nurse discharge coordinator or assessment officer will organise this.

It can take from a few days to a few weeks to plan a discharge. This depends on how many services need to be arranged.

If you have been treated in a private hospital, you may need to contact local authorities yourself to arrange a needs assessment (see page 10).

## Planning the care you need

The care that is planned for you will depend on your individual needs. It is important that you and your family members or carers are involved as much as possible in these plans. Try to be honest with healthcare staff. Tell them as much as you can about any worries you have and the help you need. This makes it easier for them to give you the right support.

### Needs assessment

While you are in hospital, the healthcare team looking after you will ask you questions. This is so they can understand your needs. It also helps them find out what support you may need when you go home. This is often called a needs assessment. Your thoughts and worries are important. So you should be involved in the needs assessment.

Your team will ask your permission (consent) before they do a needs assessment. They will also ask you if the information can be shared with other healthcare professionals and organisations.

## Questions you might be asked

- Do you live alone?
- Do you have someone who can take you home?
- Do you have family or friends who can help you when you get home?
- How do you manage with personal care, such as bathing and washing?
- Do you think you will be able to prepare your own meals at home?
- Can you manage steps or stairs, and is there a bathroom downstairs at home?
- Do you think you will need financial support?
- Do you have any pets that will need looking after?

If you do not feel confident understanding or speaking in English, the hospital may be able to arrange an interpreter. They can be there when you meet the healthcare team.

If you have any speech or hearing problems, you can ask the doctors or nurses to write things down. If you have sight problems, you can ask for information in large print. A family member or friend may also be able to help you with the needs assessment.

## Discharge plan

After the needs assessment, your healthcare team will plan for your discharge. This is often called a discharge plan. It may include:

- the name of the person who is co-ordinating the plan
- details of the treatment and support you will get when you go home
- names and contact details of who will provide the support
- details of when, and how often, the support will be provided
- names and contact details of who to contact if there is an emergency, if things do not happen as they should or if you need help out-of-hours.

You can ask the ward staff for a copy of your discharge plan if you have not received it before your discharge.

'When I came home, that was the terrifying part. You miss the all-round support that you get. But they did say to me "If you have any worries, just ring us.'

**Hugh**

## Holistic needs assessment

You may have a holistic needs assessment before going home. Your key worker will ask you questions about how you are feeling and the help you need. They will then create a care plan which includes ideas to manage your concerns and contact details for helpful organisations or services.

We have more information that you might find useful in our booklet **Holistic needs assessment: planning your care and support** (see page 45).

## Care plans

Everyone with a long-term condition should have a care plan if they want one. A care plan is an agreement between the person who is ill and health or social care professionals. It lists the services and support you will get after treatment or after leaving hospital. It also includes information about what you can do to manage your day-to-day health. Ask your key worker, specialist nurse or social worker if a care plan has been organised for you.

## Involving your carers

If you have family or carers who will be looking after you, they should be involved in the needs assessment and discharge planning. Caring can be hard work, both physically and emotionally. Your carers may need help to support them in their caring role when you go home.

If your stay in hospital is planned, you and your carer can think about the things you are likely to need help with when you go home. You can discuss these with your healthcare team before you go into hospital.

You might be worried about being a burden to your family or friends. But support from other services means your carers will have the help they need to care for you.

Our booklet **Looking after someone with cancer** has more information for carers (see page 45).

# What type of support am I likely to need?

The type of support you need will depend on the reason you have been in hospital. You might have had treatment such as surgery or chemotherapy. Or you might have been in hospital because of problems caused by cancer or its treatment. This is called symptom control.

You may need help with some or all the following:

- personal care – bathing, dressing and going to the toilet
- domestic chores – cooking, cleaning and shopping
- home adaptations and equipment – a raised toilet seat, shower seat, hand rails, pressure-relieving cushions or a stair lift
- healthcare – help with dressing wounds, injections, medication or specialist support for controlling symptoms
- emotional care – company or counselling
- finances – call our financial team on **0808 808 00 00** for guidance on what financial help or benefits you may be able to get.



# Which professionals will be involved in my care?

## Medical support

Before you leave hospital, you may be given a letter to take to your GP. It is important to make sure your GP gets the letter as soon as possible. If you are not given a letter to take with you, your hospital team should have contacted your GP electronically. You could check this with the hospital staff. You can also ask for a printed copy of this letter.

The letter will include information about:

- the type of treatment you had in hospital
- your future care needs
- any medicines you are taking
- any changes that have been made to your medication.

You should also be given telephone numbers for your hospital team in case you need to contact them. We have a table that you could use to write their contact details in (see pages 32 to 34). Your hospital team will tell you if you need to contact them directly about certain medical worries after you go home. It is important to follow the advice you are given.

## GP (general practitioner)

Your GP may have been the first healthcare professional you had contact with. They are responsible for the health of people who are living at home.

If you have been told to book an appointment with your GP after you leave hospital, it is important to do this. Always tell your GP you have been in hospital having treatment for cancer. It is important to let them know if you are still having chemotherapy or other cancer drugs.

Your GP can:

- assess if your health has changed
- help you manage side effects
- help you manage symptoms
- do home visits if you need them
- prescribe medicines and arrange repeat prescriptions
- give you information and support
- organise nursing help if needed, such as district nurses, or specialist palliative care nurses
- refer you to other health professionals, such as a physiotherapist or occupational therapist (OT).

## District and community nurses

District nurses work closely with GPs. They can regularly visit patients and their families at home. They provide help, advice and support with the practical aspects of nursing care.

Your ward nurse or keyworker may contact your local district nursing service before you go home to arrange a home visit. Not everyone needs this type of help. If you are well enough to go to your GP surgery to see a practice nurse, for example to have stitches taken out, you will not need a district nurse visit.

A district nurse or a community nurse will assess your healthcare needs. Community nurses work with district nurses to care for people at home.

The district nurse can:

- support you and a carer, and give advice to keep you as independent as possible
- help you manage your medicines at home
- give injections, change wound dressings or remove stitches
- help with managing stomas, catheters, feeding tubes and central lines
- give advice on eating well (nutrition), looking after skin and pressure areas, and bowel or bladder problems
- refer you to other health or social care professionals you may need.

The district nurse can also arrange equipment to be delivered. They will show you how to use it safely. This includes a:

- commode
- special mattress
- bedpan
- hoist or sling
- hospital bed.



## Occupational therapist (OT)

OTs can look at how you manage day-to-day activities. They can suggest and arrange practical changes to make your home safe, comfortable and easy to live in.

OTs can also arrange support if you have difficulty moving around or doing everyday activities. These activities might include dressing, washing and cooking. They can also show you how to save energy while doing these activities.

If you might need adaptations or equipment, a hospital OT will assess you while you are still in hospital. They might also assess whether you need help doing everyday activities.



Sometimes they need to visit your home to assess your needs. If this happens, it can be done with you, or a family member or carer. Sometimes the hospital OT will ask a community OT to do this assessment when you go home.

After the assessment, the OT will give you information about adaptations, aids or equipment that might be right for you. If you agree, they can arrange any equipment you need for when you go home. Adaptations to your home can sometimes take a while to put in place. You may be discharged before these are done, but only if it is safe for you.

The OT may think it would help for carers to come and help you with your personal care or preparing meals. If they think this is needed, they will refer you to the social work department who will organise this.

'When I was first diagnosed with cancer and my OT came to my home, it was like someone waving a magic wand. Within weeks all sorts of things had been installed.'

**Valerie**

## Physiotherapist

If you have problems walking or moving around while you are in hospital, you will be referred to a physiotherapist. The physiotherapist will assess your needs. They will then work with you to improve how you get around (mobility) before you go home. If you need mobility aids (such as a walking frame) when you go home, they can also arrange this.

If they think you will still need physiotherapy when you go home, they can arrange an outpatient appointment at the clinic for you. Sometimes, they may arrange for community physiotherapy.

## Dietitian

You may see a dietitian while you are in hospital. A dietitian can review your diet and talk to you, your family or a carer about any special diet you may need when you go home. They can give you advice on which foods are best to help your recovery. They can also provide food supplements if you need them. You may be referred to a community dietitian who will visit you when they go home.

## Preparing meals

If you need help to prepare meals, your family or carers may be able to help. Or you can talk to social services (see pages 25 to 26). It may be possible for you to have meals provided at home (sometimes called meals on wheels). This service usually has to be paid for. They offer different meals that can be made to suit your cultural and religious needs and any special dietary needs. There are also commercial companies that deliver the same type of service.

## Continence adviser

If you are having problems with leakage (incontinence) from your bladder or bowel, it can be difficult to manage. It can also be upsetting for you. Your district nurse will give you information on how to manage this. They can supply things like pads to help you. They can also refer you to a clinic to see a continence adviser if you need to. A continence adviser will assess your problems. They can give advice about different products you can use to help manage continence problems. You may also be able to get help with laundry services (see page 26). You can get more information from the Bladder and Bowel Community (see page 52).

## National Key Scheme for toilets

This offers disabled people access to around 9,000 locked public toilets across the UK. You can buy a key for £4.50 (including postage and packaging) from Disability Rights UK. In Northern Ireland, you can buy these keys at any local council office. Visit [disabilityrightsuk.org](http://disabilityrightsuk.org) for more information.

## Just Can't Wait toilet card

The card allows you to use toilets in shops, pubs and other places, without them asking difficult and embarrassing questions. You can get this card from The Bladder and Bowel Community (see page 52).

## Macmillan toilet card

Macmillan also makes a toilet card that may help you get urgent access to a toilet. You can order one from our website, visit [be.macmillan.org.uk](http://be.macmillan.org.uk)



# If you need specialist help with symptoms

## Palliative care team

When you go home from hospital, you may need specialist help with symptoms caused by the cancer, such as pain. Your GP, hospital doctor, nurse or keyworker can refer you to a community palliative care team.

Palliative care teams include nurses and doctors who specialise in controlling symptoms and giving emotional support. They are usually based in hospices and visit people who are being cared for at home. They work closely with GPs, district nurses and other hospital services. Palliative care nurses do not provide physical (hands-on) care.

If you need to, they may also arrange for you to go to a day centre, if your local hospice has one.

We have more information about controlling the symptoms of cancer in our booklet **Managing the symptoms of cancer** (see page 45).

## Macmillan nurses

Macmillan nurses specialise in controlling symptoms caused by cancer, and giving emotional support. They also support people going through cancer treatment. Some Macmillan nurses have expert knowledge of a particular type of cancer. They may be based in hospitals, hospices or sometimes in the community. Macmillan nurses do not provide physical (hands-on) care.

## Private care

Some people can get help at home from a private nurse. But this can be expensive. There are many private nursing agencies. You can ask the GP, district nurse or your local social services for advice. Look in your local phone book under 'nursing agencies' or search online. The Care Quality Commission can check the standards of care in nursing agencies. Visit [cqc.org.uk](https://www.cqc.org.uk) for more information.

## Social services

A social worker is responsible for assessing what practical and social help you need. A social worker may sometimes be called a care manager. While you are in hospital, you may be referred to a hospital social worker, care manager or assessment officer if you need help with:

- preparing meals
- personal care such as washing and dressing
- finances.

## Getting a social care needs assessment

A social worker can visit you to do a needs assessment.

The local authority will then decide if they will provide any services. Each local authority has its own eligibility criteria, so the services that are provided will be different depending on where you live (see page 25).

If the local authority agrees that you have high needs, it must provide you with services to meet those needs. Help can be provided by social services or arranged with other organisations such as charities. The services they might provide include:

- meals at home (meals on wheels)
- home care (home-helps and personal care assistants)
- someone to sit with you while your carers have some time for themselves (sitting service)
- equipment and adaptations to your home
- benefits advice
- a laundry service for people with incontinence
- holidays
- respite care for carers, to give them a break.

Some services are paid for by the NHS, so they are free of charge. But you may need to pay for other services. You will have a financial assessment (means test) to see if you have to pay anything.

# Your medicines

If you need medicines when you go home, your hospital doctors will arrange for you to have enough for 1 to 2 weeks.

You will need to get a repeat prescription for any medicines you need to keep taking. For most medicines, you can get this from your GP. But some drugs, such as chemotherapy or other cancer drugs, can only be prescribed by your hospital doctor. They are only given out by the hospital pharmacist.

Make sure you ask your GP surgery for your repeat prescription before your medicine runs out. This is because it can take up to 48 hours for your prescription to be ready to collect.

Prescriptions are free in Scotland, Wales and Northern Ireland. In England, prescriptions are free for people with cancer. If you need prescriptions for anything related to cancer or its effects, you can apply for an exemption certificate. You need to fill in a form called an FP92A, and get it signed by your GP. You can collect one of these from your GP surgery or hospital clinic.

## Taking your medicines

Always take your medicines exactly as they have been prescribed by your doctor. This is important to make sure they work as well as possible for you.

You might find it difficult to remember what drugs to take and when to take them. If this happens, you may find it easier to use a pill organiser (dosette box) or a calendar blister pack.

- **Pill organisers** have boxes for the day and time your medicines should be taken. You can get them from most pharmacies, but your GP has to arrange it. You, a family member, friend or carer will need to fill the pill organiser with your medicines.
- **Calendar blister packs** come pre-prepared by the pharmacy. They have the day and time when the medicine should be taken on the pack.

Talk to your hospital team if you think a pill organiser or calendar blister pack will be helpful for you when you go home.

Your treatment may be in the form of medication that you take on a regular basis. Or you may be prescribed medication to help with side effects.

You might find it helpful to write down the details of each of your medications, like in the example below.

### Medication record

Medication
Reason for taking
Instructions on how to take it (eg with food, empty stomach)
When to take it (eg morning/evening/daily)
How much to take (the dose)

The Macmillan Organiser has more information and tools for recording key contacts, appointments, medication and symptoms. See page 48 for more information.

## Oxygen treatment

Oxygen treatment is only suitable for some people. If your doctor thinks you need oxygen at home, they will prescribe it for you.

There are different ways to have oxygen:

- If you only need oxygen for short periods of time, your doctor may recommend you use an oxygen cylinder.
- If you need it for longer periods, the hospital may supply an oxygen concentrator. This is a machine that takes oxygen from the air.

You have the oxygen using a face mask or through small tubes that sit under the nostrils (nasal cannula).

Oxygen can be a fire hazard, so it is important to use it safely at home. Never smoke or use flammable products. Always keep the oxygen more than 6 feet away from flames and heat sources.

If you need oxygen when you go to appointments, you can get a small moveable (portable) cylinder to take with you. You can also go on holiday when using oxygen. You must plan ahead and make suitable arrangements.

You can find out more about oxygen treatment from the British Lung Foundation or **NHS.UK** (see pages 49 and 52).

We have more information about travel in our booklet **Travel and cancer**. And we have more information about breathlessness in our booklet **Managing breathlessness**. See page 45 for ways to order these.

# Key contacts

Before you are discharged from hospital, you will get a list of names and contact details to use if you are worried when you get home. It is important to keep these somewhere safe so you or a family member, friend or carer can use them.

It is normal to feel worried about being discharged from hospital. Making a list of the contact details of people involved in your care at home can make you feel less nervous.

You can use the table on pages 32 to 34 to record the contact details of the different people who may be involved in your care at home. You may not need contact details for all of them. There are blank spaces so you can add other people's details, if you need to.

You may find it useful to use the information about health professionals on pages 16 to 23 when filling in the table.



<b>Support service</b>	<b>What they can help with or provide</b>	<b>Name and number</b>
<b>Keyworker (may be clinical nurse specialist)</b>	Information, advice and support.	Name: Tel:
<b>GP practice</b>	Ongoing medical support and prescriptions.	Name: Tel:
<b>District nurses</b>	Nursing care, information, advice and support.	Name: Tel:
<b>Occupational therapist (OT)</b>	Practical help and equipment to make your home safe.	Name: Tel:
<b>Physiotherapist</b>	Help with mobility. Provide aids such as a walking frame.	Name: Tel:

<b>Support service</b>	<b>What they can help with or provide</b>	<b>Name and number</b>
<b>Social services – care manager</b>	An assessment of practical and social needs. Arrange services such as home care and respite care.	Name:  Tel:
<b>Dietitian</b>	Information about diet and the best foods or supplements.	Name:  Tel:
<b>Community palliative care team</b>	Specialist help with pain and symptom control, as well as emotional support.	Name:  Tel:
<b>Continence adviser</b>	Advice and information about aids and equipment to help you with any continence problems.	Name:  Tel:

<b>Support service</b>	<b>What they can help with or provide</b>	<b>Name and number</b>



# My hospital discharge check list

You may find it helpful to use this checklist before you go home from hospital. You can tick off the things you know have been done.

- If you have family or carers, do they know when you are going home?
- Do you have someone who can take you home? Or has your hospital transport been arranged?
- Will there be someone to meet you when you get home? Or do you have keys to get in?
- Will there be food in the house? Will the heating be on (if needed)?
- Do you understand how to take any medicine or dietary supplements you need to take at home?
- Do you know when your next outpatient appointment is?
- Do you know what care has been arranged for you when you go home?
- Do you have contact details for all the people who will be providing support?
- Do you have a contact number for your hospital team or keyworker (see pages 32 to 34)?

- Do you have all the equipment or items you need to use at home, such as continence pads or stoma bags?
- Has your GP been told when you are going home?
- Have you been given a letter about your care to give to your GP, or has one been sent to them electronically?
- Do you know who to contact when you are home if you do not feel well (especially after chemotherapy or surgery), have a temperature, are sick or are in pain (see pages 32 to 34)?
- Have you been given a fit note (Statement of Fitness for Work) if you need one?

'I found it confusing as to how my care was going to be organised. It took me a while to find my way round the system and know who to ring if I had a problem.'

**Margaret**

# When I get home

Before you leave hospital, your cancer doctor or specialist nurse will usually give you some advice to follow. The advice will depend on why you went in to hospital. For example, if you had surgery, they will give you advice on looking after your wound and spotting signs of an infection. They may also give you advice on activities you should not do, such as lifting or driving.

If you have had treatments such as chemotherapy, radiotherapy or targeted therapy drugs your cancer doctor or specialist nurse will explain the possible side effects.

It is very important to follow the advice you are given by your hospital team. This includes who you should contact (and what number to use) if you are worried or have problems at home (see pages 32 to 34).

## Risk of infection after chemotherapy

Chemotherapy can reduce the number of white blood cells. Developing an infection when you have a low number of white blood cells can sometimes be a serious complication of chemotherapy.

Most people do not have any serious problems with infection. Some chemotherapy treatments are more likely than others to reduce the number of your white blood cells. Your doctor may prescribe you antibiotics and other medicines to take during chemotherapy to prevent an infection. These are called prophylactic drugs.

Before you leave hospital, a nurse will talk to you about infection and show you how to check your temperature. You can have an infection without having a high temperature. Drugs such as paracetamol lower your temperature. This means they can hide an infection.

Always contact the hospital (see pages 32 to 34) on the 24-hour contact numbers you have been given and speak to a nurse or doctor if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection), diarrhoea or feeling shivery and shaking.

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (see page 45).



## If you have a wound

When you are at home, you will need to check your wound. It is important to follow any advice that you have been given by your cancer doctor or specialist nurse. You may also have a district nurse who checks your wound, to make sure there is no infection and it is healing well.

If you have any signs of infection, contact your GP, specialist nurse or cancer doctor straight away. These can include:

- redness, tenderness or a change in colour over the wound, around the scar, or both
- fluid coming from the wound (discharge)
- a temperature above 38°C or above 100.4°F (a fever)
- uncontrollable shivering (rigors)
- feeling generally unwell.

Your nurse or doctor will look at the wound and may take a swab to send for testing. They may prescribe antibiotics to treat an infection.

# What other support is available?

## Voluntary organisations and charities

Voluntary organisations and charities are important in providing help and support to people at home, and their carers. The help they offer includes:

- information
- loans of aids and equipment
- grants for aids and equipment
- holiday schemes
- financial help
- counselling
- transport
- befriending.

Your specialist nurse or keyworker should be able to tell you about local voluntary organisations and charities. You can also speak to our cancer support specialists on **0808 808 00 00**.

## Counselling support

You may need emotional support as well as practical help when you go home. You might feel worried or scared. It is natural to feel like this when you are not sure what is going to happen. It may make you feel irritable, anxious and frightened.

There is specialist help available if you need help coping with difficult emotions. Many people find it easier to talk to someone who is not directly involved with their illness.

If you would like to be referred to a counsellor, speak to your specialist nurse or cancer doctor about this before you go home. They can refer you to a doctor, counsellor or social worker who specialises in the emotional problems that affect people with cancer.

We have more information about emotions in our booklet **Your feelings and cancer** and in our booklet **How are you feeling? The emotional effects of cancer**. See page 45 for ways to order these.

## Patient support groups

After you come home from hospital you might find it helpful to talk to others who have been in a similar situation. Joining a support group for people affected by cancer can give you or your carers the chance to talk to others who understand what you are going through. The nurses in the hospital may be able to give you information about local support groups. For more information about support groups, call our cancer support specialists free on **0808 808 00 00**.

You may want to join an online support group or chat room for people affected by cancer. On our Online Community, you can speak to people in our chat rooms, talk about your experiences, share your thoughts and feelings, make friends and join support groups. See page 47 for more information.



# About our information

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

## Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

## Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

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

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

## Information centres

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

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

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

## Talk to others

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

## Support groups

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

## Online Community

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

## The Macmillan healthcare team

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

## Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit [publications.macmillan.org.uk](https://www.macmillan.org.uk/publications) and search 'book reviews'.

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

Mal



## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

## Help with work and cancer

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

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

### Macmillan Organiser

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

# Other useful organisations

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

## Support for people going home from hospital

### British Lung Foundation

**Helpline** 03000 030 555

(Mon to Fri, 9am to 5pm)

**www.blf.org.uk**

Supports people affected by any type of lung disease.

### British Nursing Association

**Tel** 0871 873 3324

**Email** [info@bna.co.uk](mailto:info@bna.co.uk)

**www.bna.co.uk**

Provides private nursing care with nurses and care assistants, who can stay with you overnight, provide respite care, practical and personal care in the home.

### British Red Cross

**Tel** 0344 871 11 11

**Textphone** 020 7562 2050

#### Email

[information@redcross.org.uk](mailto:information@redcross.org.uk)

**www.redcross.org.uk**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### Carers Trust

**Tel (England)** 0300 772 9600

**Tel (Scotland)** 0300 772 7701

**Tel (Wales)** 0300 772 9702

**Email** [info@carers.org](mailto:info@carers.org)

**www.carers.org**

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

**Carers UK  
Helpline  
(England, Scotland, Wales)**

0808 808 7777

(Mon and Tue, 10am to 4pm)

**Helpline (Northern Ireland)**

028 9043 9843

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK.

Has an online forum and can put people in contact with local support groups for carers.

**Disabled Living  
Foundation (DLF)**

**Helpline** 0300 999 0004

(Tue to Thu, 10am to 4pm)

**Email** [helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)

**[www.dlf.org.uk](http://www.dlf.org.uk)**

Provides free, impartial advice about all types of disability equipment and mobility products.

**General cancer support organisations**

**Cancer Black Care**

**Tel** 020 8961 4151

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

**Cancer Focus  
Northern Ireland**

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email**

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland.

**Cancer Research UK**

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

**Cancer Support Scotland****Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

**Email** info@

cancersupportscotland.org

**www.****cancersupportscotland.org**

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

**Macmillan Cancer Voices****www.macmillan.org.uk/  
cancervoices**

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

**Maggie's Centres****Tel** 0300 123 1801**Email**

enquiries@maggiescentres.org

**www.maggiescentres.org**

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

**Tenovus****Helpline** 0808 808 1010

(Daily, 8am to 8pm)

**Email**

info@tenovuscancercare.org.uk

**www.****tenovuscancercare.org.uk**

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

## General health information

### Bladder and Bowel Community

**Tel** 0192 635 7220

#### Email

[help@bladderandbowel.org](mailto:help@bladderandbowel.org)

**[www.bladderandbowel.org](http://www.bladderandbowel.org)**

Provides information, advice and support for a range of symptoms and conditions related to the bladder and bowel.

### Health and Social Care in Northern Ireland

**[www.hscni.net](http://www.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### NHS Direct Wales

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

### NHS Inform

**Helpline** 0800 22 44 88

(Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)

**[www.nhsinform.scot](http://www.nhsinform.scot)**

NHS health information site for Scotland.

### NHS.UK

**[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website.

Has service information for England.

### Counselling

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

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

#### UK Council for Psychotherapy (UKCP)

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)**

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

## Emotional and mental health support

### Mind

**Helpline** 0300 123 3393

(Mon to Fri, 9am to 6pm)

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**www.mind.org.uk**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans

**Helpline** 116 123

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**www.samaritans.org**

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial or legal advice and information

### Benefit Enquiry Line

#### Northern Ireland

**Helpline** 0800 022 2450

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

**Textphone** 028 9031 1092

**www.nidirect.gov.uk/money-tax-and-benefits**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

### Carer's Allowance Unit

**Tel** 0345 608 4321

**Textphone** 0345 604 5312

(Mon to Thu, 8.30am to 5pm, Fri, 8.30am to 4.30pm)

**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.

## **Citizens Advice**

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

### **England**

**Helpline** 03444 111 444  
**www.citizensadvice.org.uk**

### **Wales**

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

### **Scotland**

**Helpline** 0808 800 9060  
**www.cas.org.uk**

### **Northern Ireland**

**Helpline** 0800 028 1181  
**www.citizensadvice.co.uk**

## **GOV.UK**

### **www.gov.uk**

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

Local councils (England, Scotland and Wales)

### **www.gov.uk/find-local-council**

Has a search function that allows you to find your local council by postcode.

## **Money Advice Scotland**

**Tel** 0141 572 0237

**Email** info@  
moneyadvicescotland.org.uk

### **www.**

### **moneyadvicescotland.org.uk**

Use the website to find qualified financial advisers in Scotland.

## **NiDirect**

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland.

## **Northern Ireland Housing Executive**

**Tel** 03448 920 902 (Mon to Fri, 8.30am to 5pm)

**[www.nihe.gov.uk](http://www.nihe.gov.uk)**

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

## **Support for older people**

### **Age UK**

**Helpline** 0800 678 1602  
(Daily, 8am to 7pm)

**[www.ageuk.org.uk](http://www.ageuk.org.uk)**

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

## **LGBT-specific support**

### **LGBT Foundation**

**Tel** 0345 330 3030

(Mon to Fri, 10am to 10pm, and Sat, 10am to 6pm)

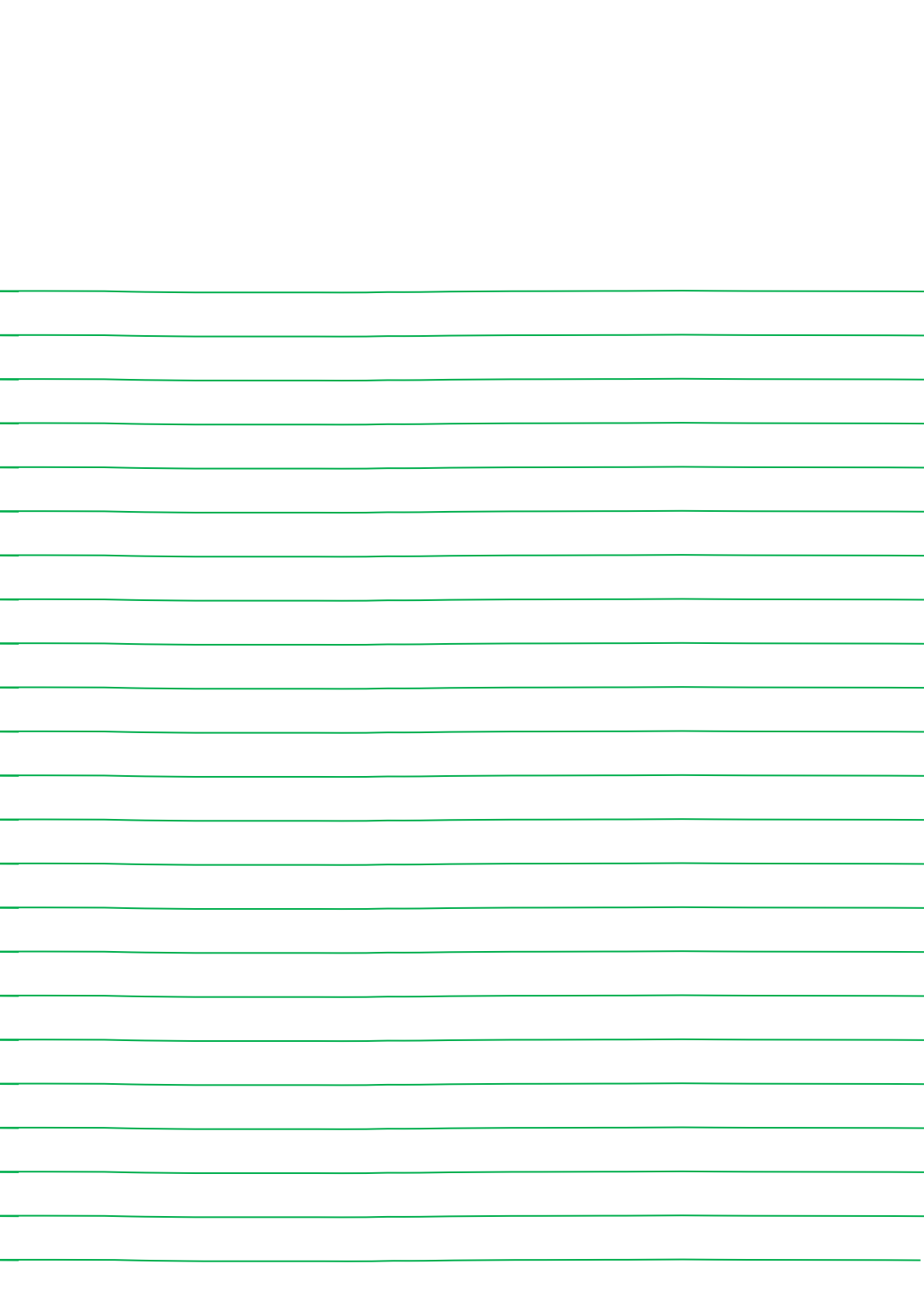
**Email** [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**[www.lgbt.foundation](http://www.lgbt.foundation)**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.







## 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 Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Tim Anstiss, Visiting Research Fellow; Nancy Bell, OG Clinical Nurse Specialist; Diana Borthwick, Lung Cancer Clinical Nurse Specialist; Iona Brisbane, Lung Cancer Nurse Specialist; Dr Charles Campion-Smith, GP and Macmillan Medical Adviser; Louise Graham, OG Clinical Nurse Specialist; Heather Jinks, Clinical Nurse Specialist.

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

We welcome feedback on our information. If you have any, please contact [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

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

Age UK. Hospital to home project. June 2013.

FirstStop. Advice for older people. Advice on hospital admissions and discharges. 2016.

NHS Choices. Your care after discharge from hospital. 2015.

# Can you do something to help?

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

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



## **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](http://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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Signature

Date

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## Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

**This booklet is about what support you can get if you are going home from hospital. It is for anyone who has had cancer or cancer treatment and is leaving hospital.**

**The booklet explains about the support that can be arranged for you when you go home. It also has information about healthcare professionals that may be involved in your care.**

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

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

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

**MACMILLAN  
CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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 <p><b>The Information Standard</b></p> <p>Certified member</p>	<p>This organisation has been certified as a producer of reliable health and social care information.</p> <p><a href="http://www.theinformationstandard.org">www.theinformationstandard.org</a></p>
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What's this logo? Visit **macmillan.org.uk/ourinformation**