Looking after someone with cancer

> “If I had advice for someone else, I'd say take all the help you can. Do all the reading you can, and just take 1 day at a time.”

Anthony, who cared for his wife Waheed

About this booklet

This booklet is about looking after someone with cancer. It explains:

- what makes someone a carer
- who can help you and the person you look after
- how to look after your own needs
- the support available when the person you look after has symptoms or side effects
- how to manage practical, legal and money issues.

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 3 to help you.

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

On pages 144 to 157, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 158 to 160).

Quotes

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

For more information

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

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

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

Am I a carer?

What is a carer?

You may not think of yourself as a carer. You may think that because you are a partner, sibling, parent, child, friend or neighbour to the person you look after, you are not a carer. But you are a carer, even if you know the person well. Understanding that you are a carer can be an important step in getting the extra help and support you need.

You are a carer if you give any unpaid help and support to someone with cancer who could not manage without your help.

Being a carer for someone can mean:

- emotional support
- helping with daily tasks
- driving them to appointments
- talking to other people on their behalf, such as health and social care professionals
- helping with personal care such as bathing and dressing.

Every caring situation is different. Your responsibilities will depend on what the person needs, and what you are able to offer. You may share caring with family or friends, or you may be the main carer. How much care you provide can change over time.

Being a carer can be rewarding. But the physical and emotional demands can be difficult (pages 110 to 116). You might have a lot of different emotions. Getting support and having someone to talk to about how you feel might help you cope.

Different health and social care professionals will support you as a carer. There are also organisations that can help.

Any adult who cares for another adult can have a carer's assessment to see what support may help (pages 37 to 38). It is important to accept help from others, such as family and friends. If you are finding it hard to cope, it is important to talk to people close to you and to your GP.

Becoming a carer can be a big change in your life. It can take time for you to adjust to the changes. It is important to look after your own wellbeing and health needs (pages 117 to 118). You may have to balance caring with other things, such as working (pages 99 to 100) and other relationships (pages 126 to 128). As a carer you may also need financial support. You may also be able to get different benefits for carers (pages 103 to 107).

If you are aged under 18 and looking after someone with cancer, you are a young carer. We have separate information at **macmillan.org.uk/young-carers**

> **"I suppose I'd describe myself as a carer, at times. I've always thought I would do anything for him, and I think I've proved that I can, and will, if I have to."**
>
> Jayne, who cared for her husband Paul

Who can help?

Support from health and social care professionals

When you care for someone, you will often have contact with health and social care professionals. They can give advice and support. They can direct you to other services.

The person you care for may have a key worker at the hospital. This is often a clinical nurse specialist (CNS). This is their main contact for information and support. But you can also contact them for advice.

When the person you are caring for is diagnosed with cancer or having cancer treatment, you may meet a:

- surgeon – a doctor who does operations (surgery)
- oncologist – a doctor who treats people who have cancer
- clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.

At other times you may also meet a:

- GP – a local doctor who treats general medical conditions
- district nurse – a nurse who gives advice and support to people by visiting them at home
- social worker – someone who can help sort out practical and financial problems
- physiotherapist – someone who gives advice about exercise and mobility
- dietitian – someone who gives information and advice about food and food supplements
- occupational therapist (OT) – someone who gives information, support and aids to help people with tasks such as washing and dressing.

It helps to write down the names and contact details of the professionals you meet. You can save them in your phone, if you have one.

Health and social care professionals need to have permission from the person you are caring for to share any information about them with you. If the person you are caring for wants to give this permission, they can tell their cancer doctor, CNS or GP. They may give you a form to sign, or they may need it in writing such as an email or letter.

Talking to health and social care professionals

Talking to health and social care professionals can feel difficult when you are a carer. But it is important to know you have a right to talk to them. Tell them you are a carer so they can involve you. This is important for your wellbeing and the person you care for.

Here are some tips to help you get the most from the appointments you both go to:

- Before you go to the appointment, talk to the person you care for about what they want to know so you both can ask questions. Also ask if there is anything they do not want to talk about.
- Write notes during the appointment to help you remember what is said. Or record conversations on your phone, as long as everyone is happy for you to do this.
- Ask professionals to explain anything that is not clear. Or ask them to repeat things if you missed information.
- If the professional cannot help you with something, ask who you should contact.

It is important that you feel you can speak freely so that you both get the right support. You do not need to speak for the person you care for, but you can help the professional understand the situation better.

As a carer, your opinion matters. You are often the person who spends the most time with them. You might be able to tell the professional about changes in symptoms, or if treatments are helping.

Speaking up for the person you look after, and being listened to as a carer, can help you feel in control and supported. It is important for your own wellbeing.

Carers UK has more information about being heard when talking to professionals (page 145). It has guides for England, Scotland, Wales and Northern Ireland.

> **"In early meetings with doctors, you're still in shock. It's hard to be present and connect with everything that you're being told. I would jot down some of the things they told us, knowing that I'd have to re-read it properly to process it."**
>
> Anthony

Advocates

If you find it difficult to talk to professionals, an advocate can help. They are independent of the NHS or adult social care services. They can:

- support you during assessments and reviews
- help you understand what the plan is for treatment or care
- help you make decisions, or challenge decisions if you do not agree
- talk to you about how you feel about assessments and decisions
- help you understand your rights as a carer.

The adult social care service at your local council has information about advocates.

How different healthcare professionals can help

It may help to understand what different healthcare professionals do, and how they can support you as carer.

GP (general practitioner)

A GP may be the first healthcare professional you have contact with.

Tell the GP of the person you look after as soon as possible that you care for them so that they can support you too. They can:

- give you information about NHS services, social services and voluntary services
- advise you about their condition and support you so you feel more confident about looking after them
- provide supporting letters and information for benefits, your local housing department or Blue Badge scheme (page 107).

Your GP can also help the person you are caring for. They can:

- assess their health and do home visits if needed
- help them manage side effects and symptoms
- prescribe medicines and repeat prescriptions
- give information and support
- organise district nurses or specialist palliative care nurses if needed
- refer them to other healthcare professionals, such as a physiotherapist or occupational therapist (OT)
- arrange for them to go into hospital if they need to be admitted, or a hospice or nursing home if you need a break from caring (respite care).

Contacting the GP

If the person you look after has a new symptom or is unwell, you may need to see the GP. If they are having cancer treatment, you may have been asked to contact an emergency 24-hour hospital number.

You can also call their key worker, which is usually the clinical nurse specialist. It is very important to follow any advice the hospital team has given you.

If the condition of the person you look after seems to be getting worse, contact the GP, hospital or key worker straight away. The GP can give you advice by phone or arrange a home visit.

GP surgeries provide a 24-hour service. If you call a doctor when the surgery is closed, you are usually put through to an out-of-hours doctor. Keep the out-of-hours number in your phone or write it down.

In an emergency, you should call 999 for an ambulance.

District and community nurses

District nurses and community nurses work closely with GPs. They visit patients and carers at home. The GP or hospital staff may contact your local district nursing service to arrange a home visit.

A district nurse or community nurse will assess the healthcare needs of the person you look after.

The district nurse can:

- support you and the person you look after, and give advice to keep them as independent as possible
- help you manage medicines at home
- show you how to wash, dress and move someone safely – if you and the person you care for are happy with this
- check their temperature, blood pressure and breathing
- give injections, change wound dressings and remove stitches
- help with managing stomas, catheters, feeding tubes and central lines
- give advice on eating well (nutrition), looking after skin and pressure areas, bowel or bladder problems
- refer you or the person you are caring for to other health or social care professionals.

The district nurse can also arrange equipment to be delivered. They will show you and the person you are caring for how to use it safely. This includes:

- commodes
- special mattresses
- bedpans
- hoists or slings
- hospital beds.

Macmillan nurse

Macmillan nurses are specialist cancer nurses. They can help people understand their cancer diagnosis and treatment. They can offer support to the person you care for and the people close to them. They can be based in a hospital, in a hospice or in the community.

In hospital, they might specialise in a specific cancer. These nurses are called clinical nurse specialists (CNS).

In a hospice or in the community, they help to manage symptoms and give emotional support. These specialist nurses are called palliative care nurses. Macmillan nurses do not usually give physical (hands-on) care.

Palliative care team

The person you are caring for may need specialist help with cancer symptoms such as pain or shortness of breath. Their GP, hospital doctor, nurse or key worker can refer them to a community palliative care team.

These teams include specialist nurses and doctors who specialise in controlling symptoms and giving emotional support. The team can also include other specialist palliative care professionals such as:

- an occupational therapist (OT)
- a physiotherapist
- a dietitian
- a social worker.

The team is usually based in a hospice, and will visit people who are being cared for at home. The team works closely with GPs, district nurses and other hospital services. Palliative care nurses do not provide physical (hands-on) care.

Marie Curie nurse

Marie Curie nurses provide free nursing care, usually during the last weeks of someone's life. They can be specialist cancer nurses or palliative care nurses. They also provide support for carers and family.

They can stay in your home overnight or part of the day, to give you a break. They are usually arranged by the district nurse or palliative care team. Marie Curie nurses are not available in all areas. It may also depend on the local trust or health board.

Private care nurse

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 checks the standards of care in nursing agencies (page 147).

Physiotherapist

If the person you are caring for has problems walking or moving around (mobility), they can be referred to a physiotherapist. The physiotherapist will assess their needs, and work with them to improve how well they move around.

The physiotherapist can also talk to you about safe ways to help with movement. They can give you information about how to prevent falls. They can help with exercises to:

- manage breathlessness
- manage stiffness in joints
- improve muscle strength and mobility.

The GP, district nurse or palliative care team can arrange a referral to a physiotherapist. Some physiotherapists visit people at home.

Occupational therapist (OT)

Occupational therapists look at practical ways of making everyday activities safer, more comfortable and easier. They visit people in their home. They can help if the person you care for has difficulty moving around or doing activities such as housework, dressing, washing and cooking. OTs can:

- assess the needs of the person you care for
- give information or advice about equipment that might help them
- provide useful equipment
- arrange adaptations to the house.

Anyone involved in a person's care can ask for an OT assessment.

Pharmacist

You may meet pharmacists at the hospital and in your local pharmacy.

Pharmacists can give you advice and information about medicines. They know how medicines work, which ones can be safely taken together and possible side effects.

A pharmacist can:

- request repeat prescriptions from the GP for you
- suggest ways of taking the medicine, if the person you care for finds it difficult
- suggest other things to help, like organising medicines into boxes for different days and times of the day
- deliver medicines to you at home
- get rid of medication you no longer need.

Boots Macmillan Information Pharmacist

A Boots Macmillan pharmacist may also be able to help if you may have some questions about medication. They are specially trained to:

- answer your questions about medication
- listen to your concerns and provide emotional support.

We have more information about finding a Boots Macmillan Information Pharmacist near you. Visit **macmillan.org.uk/boots-info-pharmacists**

Psychologist or counsellor

If you are struggling with your feelings, it is important to talk to your GP. They may be able to refer you to a psychologist or a counsellor.

Counsellors are trained to listen and help people talk through their problems. They will not give advice or answers, but they can help you find your own ways to solve problems.

A psychologist is trained to understand what people think and feel and how they behave. They can help you look at these thoughts and behaviours and find ways to cope.

Some organisations that support people with cancer, such as Maggie's centres, may offer psychological support (page 146).

Continence adviser

If the person you are caring for has problems with leakage (incontinence) from their bladder or bowel, your district nurse can give you advice. They can also arrange for a referral to a clinic to see a continence adviser. A continence adviser is a specialist nurse or physiotherapist who gives advice and support to people with continence problems. They can assess the problem and give you advice and information about aids to manage it.

Age UK has information on how you can get free incontinence products (page 154). You may also be able to get help with laundry services. You can get more information from Bladder and Bowel UK and the Bladder and Bowel Community (page 146).

If the person you are caring for needs urgent access to a toilet when they are out, we have a free toilet card that may help. Visit **macmillan.org.uk/toilet-card**

Planning and organising care

Some of these health and social care professionals will be involved in planning the care and support of the person you look after. They should talk to you to find out what help and support you need to look after the person you care for.

Going home from hospital

If the person you look after is in hospital, help and support is usually arranged before they go home. Tell the healthcare team that you are a carer, so that you can be part of the plans for going home. They may have a discharge planning meeting. They may invite:

- the person you look after, and you as their carer
- the doctor in charge of their care
- specialist nurses
- an occupational therapist (OT)
- a social worker.

> "There were lots of things that needed to be organised. I needed to get the children back from the people who'd been looking after them, and just get things organised around the house."

Anthony

The hospital staff should contact the hospital discharge team or adult social care services to arrange a discharge assessment for the person you look after. They may visit them in hospital, or they might visit the house of the person you look after to find out what help and support is needed. Then they can make the plan. This might be called a discharge plan. The person you look after should be given a copy. The plan should include details of:

- 24-hour emergency contact details if you need urgent help, or the person you look after becomes unwell
- any help from the community healthcare team, such as district nurses, and their contact details
- what treatment and support they will provide and how often they will visit
- any equipment and aids, such as a raised toilet seat or mobility aid
- changes made to the home, such as rails in the bathroom.

Before the person you look after leaves hospital, the hospital team should check that:

- they have transport to get home
- they can get in
- someone will be there, if needed
- they have the medicines they need and information about how to take them.

The hospital team will send a discharge letter to their GP. This describes why they were in hospital, their treatment and the follow-up plan.

If there is anything you are concerned or not sure about, talk to the healthcare team. They may suggest a carer's assessment to make sure you are getting the help and support you need (pages 37 to 38).

Holistic needs assessment

The person you look after might also have a holistic needs assessment (HNA). This is a separate assessment to find out what help and support a person with cancer needs. It can be done on paper, or online. The online version is called an eHNA.

HNAs are often done at key moments, such as at cancer diagnosis or at the end of treatment. But they can be done at any point, when needed.

The questionnaire has a list of concerns. They might be:

- physical
- emotional
- practical
- financial
- spiritual.

The person is asked to give a score out of 10 for how much each concern affects them. Then they have a conversation with a professional about these concerns. This might be their key worker. The person you look after can have you there for the HNA.

Then the healthcare professional will make a personalised care and support plan. This should help address the concerns and provide details of other services that might be able to help. The person you look after and their GP should get a copy of the plan. If the person you care for is not offered an HNA, you can ask someone from their healthcare team about it.

We have more information about having an HNA in our booklet **Holistic Needs Assessment: Planning your care and support** (page 138). Or visit **macmillan.org.uk/hna**

Care and support plans

Care and support plans are for anyone who needs care, or for anyone that looks after someone else. They are an agreement between:

- you
- the person you look after
- their health and social care professionals.

To get a care and support plan, contact the local council adult social care service. They will arrange a needs assessment for the person you look after, and a carer's assessment for you (pages 37 to 38). If you do not want a carer's assessment, the council can still give you information on getting support.

A care and support plan for the person you look after should include:

- the type of support needed
- how this support will be given
- how much money the council will spend on their care.

This means the person you look after can:

- stay as independent as possible
- have as much control over their life as possible
- do the things they enjoy
- know what type of care is right for them
- understand their health condition and care needs better.

It also helps you and others involved in their care understand how you can help.

It is important you understand everything in the care plan. If you are not sure about anything, ask. If the person you look after is offered care from other people, check whether there are any costs to pay.

A carer's assessment might recommend that you get help with managing the practical tasks at home. It may also list benefits that you are eligible for, and local support groups for carers.

The care and support plan should include the details of the care you will provide, and the support you need to:

- carry out this care
- stay in work or education
- have free time to relax.

The care plan should be reviewed over time to make sure it still meets the needs of both you and the person you care for.

If you are unhappy about care provided by a care agency, talk directly with the agency first. If social services has arranged your ongoing care, you can also talk with a social worker at your local social services department.

Age UK has more information on raising concerns or making a complaint (page 154).

Respite and replacement care

The carer's assessment (pages 37 and 38) can sometimes recommend someone that can help take over caring for a while so you can take a break. This is called respite care and can vary depending on your situation.

Respite care includes:

- someone who can sit with the person you care for
- care in a day care centre
- a carer coming to the house
- a short stay in a care home.

It should also have a plan for if you are unable to look after the person you care for because you:

- are returning to work or education
- are unwell
- have an emergency.

This is called replacement care. You should check if there would be any costs involved in respite or replacement care.

Help from adult social care

There are many ways the adult social care service at your local council can help you and the person you look after. They can offer practical and emotional support. They can direct you to many other services in your local community.

A social worker can assess the practical, financial and social help you and the person you look after need. They are also trained in offering emotional support. Some social workers are based in hospitals or hospices. The GP, cancer doctor, or a nurse involved in the person's care can usually arrange a referral for a social worker.

Getting a needs assessment

Before the person you look after can get help, they should have a needs assessment. To ask for a needs assessment, contact the adult social care service at your local council. You can call them, or do it online. Search **gov.uk** for 'needs assessment social services'.

A social worker or occupational therapist usually does the assessment as a home visit. Sometimes they do it by phone. They ask the person you look after how they manage everyday activities, like washing, dressing and preparing meals. An assessment of the house might also be needed.

What happens during a needs assessment

It is important the person you look after gives as much information as possible. It may help to talk about everyday activities and write down things that they find difficult. You should do this before the assessment.

An assessor should ask if there is anything that could make communicating easier, such as an interpreter. If the person you look after finds communicating difficult, you can speak for them, if they wish. You can also take notes during the assessment.

The assessment should contain as much information as possible about the person you look after. It should include:

- how the person you care for likes to be addressed and identified
- their preferred name
- their life, family, friends and pets
- where they live and who they live with.

It should try to support their independence and interests. They should be involved in decisions as much as they can, and listened to with respect.

The assessment should recognise the needs based on their:

- age
- abilities
- gender identity
- sexuality
- religion, culture and beliefs.

It should consider advice from other organisations with expertise in order to provide services that can meet these needs. It should also look at how cultural and religious needs might affect:

- the clothing they want
- how they like personal care to be given
- treatment decisions
- food choices.

If services are needed urgently, you may be contacted within 24 hours. If needs are less urgent, it can take 1 week or sometimes more. The assessor will keep you updated.

Help can be provided by adult social care services or arranged with other organisations such as charities. It might also include what care and support will be provided by you and other friends, family and neighbours. It might explain:

- what information will be shared
- why other things are kept confidential
- what this means for the best interests of the person you look after.

It is important that you understand the results of the assessment and why decisions were made. If there is anything you are concerned or unsure about, ask the assessor.

Services might include:

- meals at home – such as meals on wheels (page 42)
- a laundry service for people with incontinence (page 42)
- equipment to help with daily activities (pages 48 to 52)
- changes (adaptations) to the house to help with daily activities (pages 53 to 55)
- advice about benefits you are entitled to (pages 103 to 107)
- someone to sit with the person you are caring for, to give you some time for yourself – this is called a sitting service (page 81)
- care for the person you are caring for, to give you a break – this is called respite care (pages 80 to 82).

How care is paid for

Some services are paid for by the NHS or the local council and are free. But the person you look after may need to pay for other services. They will have a financial assessment (means test) to see if they have to pay anything.

A means test is done by a financial assessment officer from the council. They ask about the finances of the person being assessed. This includes:

- money earned through work
- pensions
- benefits
- savings
- property.

If the person you look after is having a means test, they will need to have bank statements and other paperwork available.

If the council is paying for the care for the person you look after, there are 2 ways this can be done:

- The council makes direct payments into their bank account each month for you to organise care services yourself. The account may be set up especially for direct payments. The council can help you choose care providers and manage the budget.
- The council organises care and sends the person you look after a regular bill to pay towards those costs.

Ask your local council for more information about means testing and direct payments. You can also visit **gov.uk** or the NHS website. Search **nhs.uk** for 'means test'.

There are situations where care is paid for by the NHS. They can provide care called reablement. This can last up to 6 weeks and is care for someone after an illness or hospital discharge. We explain more about reablement in our booklet **Going home from hospital** (page 138).

If the person you look after needs a lot of ongoing care in their own home, they may be able to get NHS Continuing Health Care (CHC). This care is paid for by the NHS. It is for people with complicated and serious medical needs. Your healthcare team can tell you about this.

Carer's assessment

If you look after someone, you can ask the adult social care services at your local council for an assessment of your needs to see what might help you. This is called a carer's assessment.

Contact the adult social services department at your local council. You can telephone or apply online. You can find out more about carer's assessments and find your local council adult social care service on the NHS website. Search **nhs.uk** for 'local council'.

Any adult who cares for another adult can ask for one. You can have this even if the person you are caring for:

- has not had a needs assessment
- has had a needs assessment but did not qualify for support.

The assessment might be in person, by phone or online. Someone employed by the council will ask how you are coping with caring. This includes the effects on your:

- physical and emotional health
- work
- free time
- relationships.

It is important to be honest about how caring affects you. If the council understands your needs, it is more likely to offer the right support. You can have someone with you during the assessment.

After the assessment, the council will write and tell you if you qualify for support. If you do, it will explain how it can help. The council may be able to help with costs, but you might need to have a financial assessment (means test) first. You might also be entitled to benefits.

The carer's assessment might recommend services such as:

- someone to sit with the person you are caring for, to give you some time for yourself – this is called a sitting service (page 81)
- care for the person you are caring for, to give you a break – this is called respite care (pages 80 to 82)
- help with housework or gardening
- attending a gym or exercise class
- a direct payment that you can spend on doing something just for you, so you can relax
- information about local carer support groups.

> **"We had no idea we were entitled to a carer's assessment, or that social care services had to make sure we got the right at-home support."**
>
> Jayne, who cared for her husband Paul

Home care service

You may get help from care workers to support you and the person you look after. This is called home care services. This gives you a break and helps you feel less tired. Care workers may also be called personal assistants or home helps, depending on where you are in the UK.

Care workers may do certain jobs around the house, or sit with the person to give you a break. Services can include cleaning, washing, cooking and shopping. They may also provide personal care, such as washing and dressing. Your local adult social care service or the Carers Trust can tell you what is available in your area and any costs involved (page 144).

You can use a home care agency to find a carer. The carer is directly employed by the agency, so they cover their training and supervision. These agencies are inspected and regulated by the Care Quality Commission (CQC) – page 147. You can search for local agencies and read inspection reports on the CQC website.

If you need help with cleaning, you could also contact a cleaning agency. Ask friends or neighbours if they know of any. Or you could look for adverts in a local newspaper or online. It is a good idea to contact a few to check if they meet your needs and to compare costs.

Meals at home service

It may be possible for the person you look after to have meals provided at home. This is sometimes called meals on wheels. This service usually has to be paid for. It may be provided by a private company or the local council. A social worker can arrange meals on wheels or another meals at home service.

The organisations can provide meals for different cultural and religious needs or for any dietary requirements. They are prepared to national guidelines and are designed to provide a balanced diet.

Meals on wheels is generally a delivery of a hot meal around lunchtime. They can also provide a sandwich and cold dessert for later in the day.

Some providers offer frozen meals. This means they can deliver more meals at once, and can deliver them at any time. The driver puts them in your freezer for you to heat up later in the oven or microwave.

Laundry service

If you are looking after someone who has problems with leaking from the bladder or bowel (incontinence), your local adult social care service may be able to provide a laundry service. Or you may be able to get a grant towards laundry costs. The adult social care service may do a needs assessment to find out what is needed.

Ask the district nurse, GP or social worker about this, or contact your local adult social care department.

Help from family or friends

Family or friends may be able to help you with looking after the person you care for. Some people may offer to help. Others might not know how to ask you, or what to do. Or they may not realise how much help you need.

Think about who you could ask and what tasks they can do. Try and talk openly about what you are doing, and how they can help.

Sharing care with family or friends means that you have time to look after yourself, as well as the person you are caring for. It can help family and friends understand your situation better.

Getting help from other people also benefits the person you are caring for. It gives them the chance to spend time with others. They may be relieved that you are getting the support you need.

Remember that friends and family might want to do things differently to you. Make sure you involve the person you are caring for and try to agree on who does what.

You can start by:

- making a list of daily activities you may need help with, such as hospital appointments, or taking children to school
- asking people what they can do to help
- asking people how much they can help.

People may want to help by:

- cooking or making extra meals you can freeze
- doing household jobs like cleaning, washing or looking after the garden
- sitting with the person you are caring for, so you can have a break

They can help the person you look after by:

- taking them out
- taking them to appointments
- helping you with their personal care.

Make sure anyone who helps has the information they need. This could include details about what the person you look after prefers to eat, or the medicines they take. It is also important to make sure they have phone numbers of who to contact in case of problems.

Using a rota or a shared calendar

You could create a record of who is helping, when they are coming and what they are doing. This can be very helpful if you do not live with the person you are caring for. But even if you do live together, it can help make the best use of everyone's time.

You might want to make a rota for the different days of the week and write in who will do each task. You may want to create a shared calendar on your phones so that everyone can see it and add details.

Carers UK has a free online and mobile app called Jointly, which you could use to co-ordinate who is doing what. Find out more and download it at **jointlyapp.com**

Caring at home

Equipment and changes to the home

Equipment and changes to the house (adaptations) can help make things easier for you and the person you look after. The healthcare team can tell you what support is available, how to get it and about any costs.

They may also arrange for the person you look after to work with an occupational therapist (OT). OTs give information, support and equipment to help with everyday tasks. The OT will assess the person you look after before they go home. They can give expert advice on what might be suitable for you and the person you care for.

They may also arrange for the person you look after to see a physiotherapist (PT). PTs give advice and support on how to help the person you look after with moving around (mobility).

The OT or PT will show you and the person you look after how to use equipment safely. They can also tell you where to position or store it. Your local council can also assess the house to see if equipment or adaptations might help. A home assessment is free. Organisations such as Living Made Easy can give you an idea of what equipment is available and where you can buy it (page 154).

You can also hire equipment:

- to see if it helps before buying
- if you only need something for a short time.

You can hire equipment from the Red Cross to help with mobility and going to the toilet (page 153).

Mobility aids

If the person you look after has problems with walking, a mobility aid might help. There are different options depending on their needs.

Walking sticks

A walking stick can help with balance. A PT or OT can advise you on which type might be best for the person you look after. For safety, the stick needs to be the correct height. You can also get left- and right-handed sticks. Some have feet, so they stand up by themselves.

Sometimes they can borrow a walking stick from the hospital. You may need to pay a deposit. Mobility shops and websites also sell walking sticks.

Walking frames (Zimmer® frames)

Walking frames give more support than a walking stick. It is important that the frame or stick is at the correct height so that it is safe to use.

Walking frames may:

- come with or without wheels
- have seats, trays or baskets attached
- fold down to fit in the boot of a car.

Your PT or OT can advise you on which type of frame is suitable for the person you are looking after.

Wheelchairs

If the person you look after struggles to walk, you may find a wheelchair helpful when going outdoors and into shops and buildings.

Your PT or OT may advise you on whether to borrow, rent or buy one. It might depend on:

- how long they might need it
- how often it will be used
- whether it is for indoors or outdoors.

If they need a wheelchair for a short time, your local Red Cross shop may be able to lend you one (page 153). Shopping centres often have ShopMobility schemes to use while you are there.

If the person you look after needs a wheelchair for a longer time, the GP, PT or OT may refer them for a wheelchair assessment. The assessment can help find out if they need one, and which type would be most suitable.

If they want to get a wheelchair on the NHS, they will need a wheelchair assessment. If they wish to buy one, they may also be eligible for a voucher to put toward the cost.

Mobility shops and websites sell wheelchairs. A Motability Scheme can help you buy or rent a powered wheelchair (page 154).

Mobility scooters

A mobility scooter can be useful for covering longer distances. They can often be folded to fit in the boot of a car. They can be expensive. You may want to think about:

- how often the person you look after will need it
- whether it will go on the road as well as the pavement
- where you might keep it
- the care and maintenance costs.

A PT or OT may give advice to help you decide.

Toilet, bathing and dressing aids

A raised toilet seat may make going to the toilet safer and more comfortable for the person you look after. If they find getting to the toilet difficult, you might want to think about having a urine bottle by the bed, or a commode.

A commode is a chair with a toilet bowl hidden underneath. The person you look after can keep it close by. If they worry about getting to the toilet at night, it may be useful to keep in their bedroom.

Equipment to make bathing safer includes:

- handrails in the bathroom
- slip mats
- shower seats.

There is equipment to help with putting on underwear, socks, tights and shoes.

Beds and chairs

If the person you look after spends a lot of time in bed, it is important they are comfortable. The district nurse can arrange:

- a pressure-relieving mattress
- an adjustable bed rest
- blocks to make a bed higher – these are called bed raisers
- a hospital bed at home.

Ask the person you look after what could make them comfortable. They may need to try different sitting or sleeping positions. Using lots of pillows can help. For example, V-shaped pillows can relieve pressure on the back. If their arms or legs are swollen, you can use extra pillows to support them and help reduce the swelling. District nurses can usually provide a pressure-relieving cushion.

An OT or PT can give you advice on the main chair that the person uses. They may be able to provide furniture raisers to make chairs higher and easier to get in and out of. They might be able to provide a more suitable chair, such as a recliner.

Breathing equipment

If the person you are caring for has breathing problems, the district nurses or palliative care team can arrange equipment to use at home. This may include an oxygen cylinder or a nebuliser. A nebuliser gives medicine as a vapour to inhale.

Other types of equipment

There are many other, smaller pieces of equipment that could help the person you are caring for. These can include things like cups with spouts and 2 handles, and cutlery that is easier to use.

Changes to the home

The OT can suggest practical changes to make the house safer, more comfortable and easier to live in. This could include putting handrails in the bathroom, or moving the bed downstairs.

It is also sometimes possible to make bigger changes. This can involve putting in a toilet or shower downstairs, or fitting a stair lift. This can take a few months of planning and involve building work. You and the person you are caring for will need to talk to an OT about any bigger changes to the home. This is to make sure you understand how the change might affect everyday life while it is being made.

The local authority might pay for the changes if the person you are caring for lives in a council or housing association house or flat.

If they own their home or rent it privately, they may still be able to get some financial help. Ask the OT, social worker or your local social services about this. You should make any claims for financial help before building work starts.

Organising their room

If the person you look after needs more care or is coming home from hospital, you may want to organise their room for them.

Here are some tips:

- Ask them which room they would like to have – they might prefer to be near the bathroom.
- If possible, position the furniture so that you can get to each side of the bed safely.
- Leave things within reach for the person you look after.
- Ask which of their things they would like in their room – for example, their computer or tablet, or special ornaments and photos.

Sleeping arrangements

It is important that you both get plenty of sleep and rest. If you are caring for a partner and usually share a bed, talk about whether this will still be comfortable for you both. You can both decide what is best.

Helpful technology

Technology can help people living with cancer to be more independent. It can also reassure you both. Carers UK (page 145) has information about the following types of technology that can help you and the person you look after:

- Personal alarms – by touching a button worn around the neck or wrist, the user can contact a 24-hour emergency response centre for help. These can be helpful if someone falls.

- Passive infra-red (PIR) detectors – these devices are placed on the walls to monitor activity. They can tell you whether the person you look after is moving around, and if someone else is there. PIR detectors can also tell you whether appliances such as the kettle are being used.
- Property exit sensors – these can tell you when people come and go from the house.
- Wearable GPS trackers – these can be useful if you worry that the person may leave the house and get lost or be unsafe.
- Cameras – you can set up cameras with motion sensors around the house or on the doorbell.
- Carbon monoxide, gas, smoke and flood detectors – sensors can detect a gas leak, fire or flood in the home, and send alerts.
- Vital sign monitoring – this can send information from heart or blood pressure monitors to a monitoring centre, and then to the person's GP or healthcare team. This can help check conditions such as asthma, heart failure, diabetes and high blood pressure.
- Medication devices – devices can remind you about taking medication and issue the correct dose at the right time. They can also lock to prevent the person taking too much medication, and send alerts if medication has not been taken.
- Bed or chair sensors – these can detect if the person has have got up but not returned in a set time. It automatically sends an alert to a carer or emergency service.

Some adult social care departments may have a technology team that can offer advice and tell you about any costs involved.

Mobile apps can also be useful. You can download them from the app store onto your phone. The Carers UK app Jointly can help co-ordinate care between several people. Find out more at **jointlyapp.com**

Managing everyday needs

The person you look after may need help with their personal care. How much you do, and what care you provide, may change over time. You may do less if they have finished cancer treatment and are recovering. Or you may do more if their cancer becomes more advanced.

The healthcare team can help you understand what to expect over time. As the person's situation changes, the team can give you information and support when you need it.

You can get help and support with personal care from different health and social care professionals. Family, friends, and neighbours may also be happy to help if the person you look after is comfortable with this. Some of the things you may need to do may make you, or the person you look after, feel uncomfortable. If this is the case, talk to the healthcare team. They may be able to arrange other services to help.

It is important that others provide personal care in a way that respects the needs of the person you look after. Make sure that others address the person you care for in the way they prefer and identify with. The care should be supported by their needs assessment (pages 32 to 38) and care and support plan (page 28) if they have one.

Washing and bathing

The social worker or district nurse may be able to arrange a care worker to help with bathing.

Or they can show you how to do it yourself. Having a regular wash, shower or bath can prevent skin problems or infections. It can also help the person feel more comfortable.

Tips for washing and bathing

- Keep to their usual routine and use products they like.
- Be safe – check the water is not too hot or cold and the floor is not wet.
- Be sensitive to feelings and mindful of their privacy and dignity.
- Allow them to safely do what they can.
- Use equipment to help, such as a shower seat or chair at the basin.

Dressing

Loose clothes may feel more comfortable. Clothing with elastic waistbands can be easier to get on and off. If the person feels hot or cold easily, layers that can easily be taken off and put back on are a good idea. Clothes that are easy to wash and dry and do not need much ironing may be more practical.

Hair care

If the person you are caring for has hair loss due to cancer treatment, you should follow the advice of their cancer team. We also have information about caring for hair during and after cancer treatment in our booklet **Coping with hair loss** (page 138).

If they cannot get out of bed easily, try using a plastic hair-washing tray. Or use a rinse-free, waterless shampoo or shampoo cap that goes directly on their hair. You remove the shampoo by drying their hair with a towel. Your local pharmacy can give you more information about these products. If the person needs a haircut, you could try to find a hairdresser or barber who does home visits.

Nail care

Some cancer treatments affect a person's nails and make them more brittle. The nurses at the hospital clinic can also give you advice. Chiropodists or podiatrists help treat foot problems may be able to make home visits.

The GP can arrange a referral to a chiropodist. This service is not always free, so check first. If the person you are caring for is diabetic, always ask a chiropodist to cut their toenails. Some voluntary groups may provide manicures or pedicures at home.

We have more information about looking after skin and nails. Visit **macmillan.org.uk/skin-nails**

Toilet needs

If the person you look after needs help to go to the toilet, it may be best for their room to be close to the bathroom. A raised toilet seat may make going to the toilet safer and more comfortable. If they find getting to the toilet difficult, they might want a urine bottle by the bed. Or they could use a chair with a toilet hidden underneath called a commode.

The occupational therapist (OT), social worker or district nurse may be able to provide these. You can also hire them from the Red Cross (page 153) or buy them. It is important that the person has privacy when using a bottle or commode.

It can be difficult if the person you are caring for has problems with leaking from the bowel or bladder (incontinence). A district nurse can give you advice about protective bed covers, urinary sheaths, pads or pants. They can also usually refer you to a continence adviser, who can give advice about different products you can use.

Adult social care may be able to provide laundry services.

You can get more information about products and services from Bladder and Bowel UK and the Bladder and Bowel Community (page 146).

Standing and walking

The person you are caring for may need your help to stand or walk. Ask a physiotherapist, OT or district nurse for advice on doing this safely and how to prevent injuries. They can provide standing or walking aids. They can also do a falls assessment to help prevent falls.

Tips on standing and walking

- Make sure there is good lighting inside the house, especially on stairs.
- Make sure there is nothing on the floor that they can trip on, such as cables or clutter.
- Use non-slip mats or rugs.
- Make sure you both wear comfortable, well-fitting shoes with a good grip.

If the person you care for has a fall, do not move them. Both of you could get hurt. Contact the GP or district nurses for advice, or call NHS **111**. In an emergency, call **999** for an ambulance.

If the person you are caring for is on their own some of the time, a personal alarm may be a good idea. It allows them to call for help by pressing a button worn around their neck or wrist to call a 24-hour response centre. The response team can alert someone to help.

Carers UK has information about these alarms and other technology that can help you and the person you look after (page 145).

Moving and turning

The person you are caring for may need help moving or turning. The physiotherapist, OT or district nurse can show you how to do this safely so you don't hurt yourself or the person you look after.

They may be able to arrange help from care workers, or provide equipment to help you. This could include special sliding sheets so you can move someone easily in bed without damaging their skin. Or you might need a hoist to lift the person up so you can position them and gently lower them into a chair or bed.

When a person is not able to move around much, they have a higher risk of pressure sores. These are most common on the bottom, back or heels in people who are in bed or sitting in the same position for long periods.

To avoid this, they need to change how they are sitting or lying regularly. If they cannot do this on their own, a district nurse can show you how to move them. They can also provide a pressure-relieving mattress and cushion, and ankle or elbow pads to reduce the risk of pressure sores. Gently massaging the person's back, arms or legs with moisturising cream keeps their skin soft.

Your local Carers Trust carers' centre may offer training in first aid and moving and handling (page 144). You could also speak to the GP or district nurse.

Help with medicines

You may need to help the person you look after take their medicines. Make sure they take them exactly as their cancer doctor, specialist nurse or GP has prescribed.

Check:

- that their name and medicine are correct on the label
- the expiry date
- when it should be taken
- how to take it, such as with food, or after food.

If you need advice and information about medicines, ask your local or hospital pharmacist (page 22).

You may find it helpful to use a pill organiser (dosette box) or calendar blister pack for regular medicines. Both have separate compartments for tablets, showing the day and time they should be taken.

A calendar blister pack comes pre-prepared by the pharmacy. Talk to the GP or pharmacist about getting one of these. It is important that you also know about any medications that are taken 'as required' and how and when to use them.

Prescriptions are free in Scotland, Wales and Northern Ireland. In England, prescriptions are free for people with cancer. If the person you care for needs a prescription 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 the GP. You can collect one of these from the GP surgery or hospital clinic.

If the person you look after is registered for patient online services with their GP, you can order repeat prescriptions through the NHS website Visit **nhs.uk** and search for 'repeat prescriptions'.

Using a medication planner

A medication planner is a good way to keep a record of what needs to be taken and when. You can use the planner on the next few pages, or download a copy from **macmillan.org.uk/medication-planner**

This planner was developed with help from Boots Macmillan Information Pharmacists.

You may have some questions about your medication. Our Boots Macmillan Information Pharmacists are specially trained to:

- answer your questions about medication
- listen to your concerns and provide emotional support.

We have more information about finding a Boots Macmillan Information Pharmacist near you. Visit **macmillan.org.uk/boots-info-pharmacists**

Medication planner

	TIME	MON
Medication:		
Dosage:		
How many times a day?		
What's it for?		
Shape/colour:	**Instructions:**	

	TIME	MON
Medication:		
Dosage:		
How many times a day?		
What's it for?		
Shape/colour:	**Instructions:**	

TUE	WED	THU	FRI	SAT	SUN

TUE	WED	THU	FRI	SAT	SUN

	TIME	MON
Medication:		
Dosage:		
How many times a day?		
What's it for?		
Shape/colour:	**Instructions:**	

	TIME	MON
Medication:		
Dosage:		
How many times a day?		
What's it for?		
Shape/colour:	**Instructions:**	

	TU	WED	THU	FRI	SAT	SUN

	TUE	WED	THU	FRI	SAT	SUN

Managing symptoms and side effects

The person you are caring for may have different symptoms, or side effects from their cancer treatment. Their cancer doctor, specialist nurse or palliative care team can prescribe drugs or give advice on managing these. Always tell them if side effects or symptoms do not improve. There are also things you may be able to do to help.

If the person you are caring for is having treatment, such as chemotherapy or other drugs, it is very important to follow the advice that the healthcare team gives you. For example, if they have a temperature or feel unwell, you may have been told to contact the hospital directly on a 24-hour number.

Understanding more about this can help you support the person you are caring for. We have more information about different cancer treatments and their side effects. Visit **macmillan.org.uk/treatments-and-drugs**

Eating problems

Eating problems and loss of appetite are common symptoms of cancer. They can also be caused by side effects of treatment, such as a sore mouth, feeling sick or difficulty swallowing.

The GP, district nurse or hospital team can give you advice or arrange a referral to a community dietitian. They can also do a home visit. They can give you advice on foods the person you are caring for could try. For example, they can give them nourishing drinks or food supplements. You can also get these from the pharmacy or on prescription.

What you can do

- Make small amounts of food often, instead of 3 meals a day. Smaller amounts of food may look easier to manage, so try using a side plate instead of a dinner plate.
- Keep snacks handy, such as bags of nuts or dried fruit, or a bowl of grated cheese. These are high-calorie (energy) foods which the person you look after can eat whenever they like.
- Add extra calories to their food using butter, full-fat milk, cream or ice cream.
- If swallowing is difficult, make them softer foods, add sauces, or make smoothies or milkshakes.
- Softer foods, such as fish, also take less energy to eat.

We have more information in our booklet **Eating problems and cancer** (page 138).

> **"I saw that mum's appetite had changed from the chemotherapy. I researched dietary tips for her, and experimented with meals."**
>
> Maymay, who cared for her mum

Sore or dry mouth

Mouth problems can happen as a side effect of treatment, or because of advanced cancer.

The lining of the mouth or throat can become thinner with ulcers.

The most common infection is oral thrush. This usually looks like white patches or a white coating over the lining of the mouth, tongue or throat. If you or the person you look after notice this, tell the healthcare team. They can treat it with mouthwash, tablets or gels.

What you can do

- Try and follow a good mouth care routine for them. Clean their teeth with a soft-bristled brush.
- Make a weak mixture of warm salt water so they can rinse their mouth.
- If their doctor prescribes a gel, spray, mouthwash or painkillers, use it as advised.
- Encourage them to drink plenty of fluids, but avoid acidic drinks like orange juice.
- Make food easier to swallow by adding liquid such as gravy, sauces or cream.
- Use lip balm or Vaseline® to keep their lips moist.
- Encourage them to avoid alcohol, tobacco and foods that irritate their mouth.

If the person you are caring for needs dental treatment, ask the dentist if they can do a home visit.

We have more information at **macmillan.org.uk/dry-mouth**

Constipation

The person you look after might be constipated if they are not able to pass stools (poo) as regularly as normal for them. Or their stools may become harder, so they need to strain to pass them.

Constipation can be caused by:

- a lack of fibre in their diet
- not drinking enough fluids
- not being active
- some medicines, such as the painkillers morphine and codeine.

Everyone's bowel pattern is different. But as a general guide, if they have not passed a stool for 3 days, you should let the healthcare team or GP know, unless this is usual for them. The team can give you advice and treatment (laxatives).

What you can do

- Try to include plenty of fibre in their diet if possible. This could be from wholemeal bread, high-fibre breakfast cereals, fruit, vegetables, beans, lentils, grains and seeds.
- Encourage them to drink at least 2 litres (3½ pints) of fluid a day.
- Encourage them to move about or do some gentle exercise if they can. This can help keep the bowel moving.
- Try natural remedies for constipation. These include apricots, prunes, prune juice and syrup of figs.

We have more information at **macmillan.org.uk/constipation**

Feeling or being sick

This can be caused by cancer or cancer treatments. If the person you look after is feeling or being sick, contact the hospital on the 24-hour number, if you have been given this advice. You can also contact the GP or specialist nurse. They can prescribe anti-sickness drugs.

There are different types of anti-sickness medicine which work in different ways. Some may work better for them than others.

Some anti-sickness drugs may make them constipated (page 71). Let their doctor or nurse know if this happens.

What you can do

You could offer:

- small amounts of food often, instead of 3 meals a day
- dry food, like crackers or biscuits
- ginger tea or ginger biscuits, which can reduce feelings of sickness
- ginger beer, fizzy mineral water or lemonade
- peppermints or peppermint tea.

We have more information at **macmillan.org.uk/nausea-vomiting**


EASY

Pain

Cancer can cause pain for many reasons. Sometimes treatment for the cancer can help reduce the pain.

Describing their pain will help the doctors and nurses find the best way of treating it. You might find using a pain diary helpful when you talk to them about the person you look after.

You can download and print a copy of a pain diary from our website. Visit **macmillan.org.uk/paindiary**

Specialist palliative care doctors and nurses are experts in helping people who are in pain.

Physiotherapists or occupational therapists can also help with practical things such as providing equipment to help make them more comfortable.

Pain is usually treated with painkillers. Painkillers can come as:

- tablets or capsules
- liquids
- nasal sprays
- skin patches or gels
- suppositories into the back passage
- injections.

The person you care for may only need to take painkillers when they have pain. Or they may need to have painkillers at regular times to keep their pain controlled.

Once their doctors and nurses have assessed the pain, they will prescribe the best painkillers to help control it. They may also prescribe other medicines to take with the painkillers. These can further reduce pain or help with the side effects of the painkillers.

If the pain or other symptoms become difficult to control at home, a short stay in hospital or hospice may help. This can help manage the pain and develop a plan to keep it under control when they go home.

What you can do

- Help them change position regularly so they are comfortable.
- Make sure they take medications on time. Sometimes regular painkillers are better than medicines taken 'as required'.
- Try other things, such as a warm bath or heat pads to soothe aches.
- Talking about pain can make coping with it easier. You can also talk to their healthcare team, GP or palliative care nurse.
- Watching TV, reading, listening to music or short visits from friends and family can all help distract them for a while.
- Help them to be active.

We have more information in our booklet **Managing cancer pain** (page 138).

Breathlessness

Breathlessness can be upsetting for you and the person you are caring for. But there are different things that can help, depending on the cause. Drugs to relieve breathlessness can be given in different ways, such as tablets, injections and inhalers.

Oxygen therapy is sometimes helpful. Some people are referred to a special breathlessness service for advice and support.

What you can do

- Help them sit in a comfortable position that supports their upper chest muscles. This may be sitting in a chair with their back upright or sitting forward with their elbows on their thighs.
- Dress them in loose-fitting clothes, especially around their waist and chest.
- Use pillows to help them sleep with their head and chest raised, if they can.
- Having cool air on their face may help ease breathlessness. Help them sit in front of an open window, or hold a fan about 15cm (6 inches) away from their face. Most people feel this helps after a few minutes.
- Encourage them to sit down while washing and dressing.
- After bathing, use a towelling bath robe or dressing gown to help them get dry. They may need help to dry their feet.
- Suggest using a baby monitor or mobile phone to talk to people in other rooms. That means they will not have to shout or get up, especially at night.
- Help them use breathing and relaxation techniques.

We have more information in our booklet **Managing breathlessness** (page 138).

Sleep problems

Many people with cancer have problems with sleeping at some point. This can be for different reasons, including anxiety or symptoms such as pain (pages 74 to 75) or breathlessness. Ask the healthcare team about ways of managing these. If they have pain, ask the doctor about painkillers that will last through the night. We have more information at **macmillan.org.uk/trouble-sleeping**

They may feel better after a short nap during the day. But too much sleep during the day can cause problems sleeping later. If possible, it might be best if they avoid sleeping in the late afternoon or evening.

Some medicines affect sleep. For example, steroids may affect the sleep of the person you look after. If this is happening, ask their doctor if the medicines can be taken earlier in the day. Sometimes a short course of sleeping pills can help to set a regular sleeping pattern, or help through a difficult time. They are best taken before bed, rather than in the middle of the night.

What you can do

- Set a routine for them by helping them go to bed and get up at about the same time every day.
- Try to have some activity during the day, if possible. This may help them feel tired and ready for sleep when they go to bed.
- Avoid large meals and stimulants like caffeine or cigarettes late in the evening. Try giving them a warm, milky drink before going to bed.
- Try a relaxing routine before bed. A warm bath or shower, reading or listening to soothing music might help.
- Make their bedroom a relaxing place to be. Create an area that is dark, quiet and comfortable, but not too warm.
- Check their mattress and pillows are comfortable. Or ask a district nurse or occupational therapist about a pressure-relieving mattress.

Other care options

Taking a break from caring (respite)

It is important to take a break sometimes. This means letting someone else care for the person you look after for a while. This is called respite care. You need to time to look after your own well-being to stop you becoming physically and emotionally tired.

You might have regular respite care, so that you can spend time doing other things each week. Or it might be for a longer time, so that you can visit friends and family or go away on holiday. Respite care options include:

- sitting services
- day centres
- short stays in a hospice, hospital, residential home or nursing home.

To get respite care, you can ask adult social care services for an assessment of your needs. This is called a carer's assessment (pages 37 and 38). A carer's assessment can also be done after a needs assessment of the person you look after (pages 32 to 38).

Charities such as The Respite Association can help with respite breaks for carers (page 145). They are usually care packages for 1 or 2 weeks at a time.

Ask your health or social care team about what is available locally. Carers Trust or Carers UK can also give information about support in your area (pages 144 and 145).

Your GP, social worker, district nurse or palliative care nurse may be able to arrange longer periods of respite care.

It is important that anyone providing respite care respects the needs of the person you look after. Make sure that they:

- address the person you care for in the way they prefer and identify with
- know who and what is important to them.

Sitting services

You might be able to arrange for someone to sit with the person you look after. This could be a morning, afternoon or evening. Sometimes they can stay overnight. Sitters may also help with housework, or personal care such as washing and dressing. Charities such as Carers Trust offer sitting services (page 144).

Day centres

The local hospice or hospital may run a day centre for people with cancer. They often provide lunch and transport to the centre. Some centres offer other services, such as activities and complementary therapies.

Short stays

There may be times when you feel you need a longer break. Your GP, social worker, district nurse or palliative care nurse may be able to arrange for the person you look after to stay somewhere. This may be in a residential or nursing home. Nursing homes provide nursing care.

Taking a break is a decision you need to make with the person you look after. It can be good for you both. During respite care, you can take a complete break or continue to visit the person you look after.

You can plan the break together. For reassurance, you may both want to visit the home and talk to the staff. You could take other family or friends as well.

Residential and nursing homes

Residential homes or nursing homes give different levels of care. A social worker, GP or district nurse can explain the difference. They can:

- tell you about local residential and nursing homes, and what care they give
- suggest things to think about when choosing a residential or nursing home
- help arrange this type of care.

Details of local residential or nursing homes are available from the adult social care department of your local council. The adult social care department can tell you about the costs involved. Before a stay in a residential or nursing home, it is important that adult social care assess you. There can be extra costs involved that you did not expect. Charities such as Age UK can offer independent advice about finding and paying for residential or nursing homes (page 154).

If the person you care for needs a lot of ongoing care, and has complicated and serious medical needs, they may be able to get NHS Continuing Health Care (CHC). This is paid for by the NHS. Your health and social care team can tell you about this.

Before you choose a residential or nursing home, it can help to talk to others who have had recent experience of the homes you are considering. The standard of care in residential or nursing homes and care agencies across the UK is checked by the Care Quality Commission (page 147). You can read the most up-to-date report at **cqc.org.uk** Or ask the health and social care team if they can get it for you.

Hospice care

Hospices specialise in managing symptoms, including pain and shortness of breath. They are smaller and quieter than hospitals. They feel less clinical and more like home. Many have sitting rooms and space for family members to stay overnight.

Most people think of hospices as somewhere people go at the very end of their life. But hospices also offer short periods of care to help with symptoms. This is called palliative care. Sometimes a hospice might offer respite care, if the person you look after has symptoms that need managing too.

Your GP, district nurse, specialist palliative care nurse or social worker may suggest that the person you look after goes to a hospice if they think it is suitable. Hospice care is always free.

You may feel upset and worry they might not be able to come home again. But after having their symptoms managed, they may be well enough to come home.

The person you look after may have already told you that they want to be cared for in a hospice at the end of their life. They may have written down what they want in an advance statement. You can both visit the hospice to talk about this and ask questions. This can help you both feel reassured, plan for the future and help you talk to friends and family.

Some hospices may have a short waiting list.

We have information about making decisions and caring for someone at the end of their life in our booklet **A guide for the end of life** (page 138).


Last will and testament

Making decisions and legal issues

Planning ahead

There are ways for people to list their wishes and choices about their care towards the end of their life. It is sometimes called advance care planning.

It is helpful for the person you look after to plan and make decisions while they are well enough to do so. Their healthcare team can tell them more about the forms they can use.

Planning ahead can help them talk to everyone involved in their care about what they want. This includes the healthcare professionals and others such as friends or family.

It can be hard to talk about these plans with the person you look after. But it can help you and others to make decisions when the person you look after is no longer able to. If the person you look after wants you to be involved in their advance care planning, the healthcare team should do this.

Advance care planning can include:

- making an advance statement
- making an advance decision to refuse treatment – this is sometimes called a living will (or in Scotland, an advance directive)
- creating a power of attorney
- making a will.

We have more information about advance care planning in our booklet **Planning ahead when living with cancer – England and Wales** (page 138). **Planning ahead when living with cancer – Scotland** can be found online at **macmillan.org.uk** We also have more information at **macmillan.org.uk/advance-care-planning**

Advance statement

The person you look after can tell you and others their wishes for their future care. They can record this in an advance statement. By writing it down, they can make it clear what they want.

This can help you, friends or family and the healthcare team make decisions in their best interest, if they are unable to. They can write it with support from you, friends or family and their healthcare team. It could be a record of a conversation with their GP or nurse.

It can include things like:

- where they would like to be cared for, for example, at home or in a hospice
- who is important to them, and how they want them to be involved in their care
- how they would like to be cared for, such as how they prefer things to be done and who should do them
- how they want any religious or spiritual beliefs to be reflected in their care
- what treatment they would prefer to have or not have
- practical things that are important to them, such as who will care for their pet.

An advance statement is not legally binding. It does not need to be signed or witnessed. But people may wish to sign it, if they can, to show that they wrote their wishes down.

The person you look after decides who can see their statement. But anyone who makes decisions about the person's care must know about it. In England and Wales, a document called Preferred Priorities for Care can be used to make an advance statement.

Advance decision (living will)

The person you look after can decide to refuse future treatments while they are well enough to make that decision. This is called an advance decision. It may be called a living will. It is also called an advance decision to refuse treatment (ADRT).

They must name all the treatments they wish to refuse in the future. They can decide to refuse a treatment in some situations, but give permission for that treatment in other situations. An advance decision needs to be clear about those points.

An advance decision can also include decisions about life-sustaining treatment. This might be:

- whether they would want antibiotics to treat an infection or a machine to help with breathing
- their feelings about treatment if their heart stops (resuscitation or CPR).

It may help to talk to the healthcare team about advance decisions. This can help the person you look after to make informed decisions. It can also help other people they want to be involved in the process.

An advance decision is legally binding. It needs to be documented that the person has the ability to make their own decisions (mental capacity).

If they want to refuse life-sustaining treatments, it must be signed by them and witnessed.

Power of attorney

If the person you are caring for wants you, or others, to manage things for them, they can arrange a power of attorney.

In the document, the person they choose is the attorney and they are the donor. They can decide if they want 1 attorney or more.

The person you look after can decide if their chosen attorneys make decisions together, or if 1 person can make some decisions.

Types of power of attorney

Power of attorney can be permanent or temporary.

Permanent

This is called:

- a lasting power of attorney (LPA) in England and Wales
- a continuing power of attorney in Scotland
- an enduring power of attorney (EPA) in Northern Ireland.

An LPA can have 2 parts, depending on the person's wishes and situation. Most people create both at the same time. The 2 parts cover decisions about:

- health and wellbeing – medical care, personal care and advance decisions
- property and finances – money, bank accounts, bills, pensions, benefits or selling property.

An EPA only covers property and finances.

Temporary

This may be is called:

- an ordinary power of attorney
- a general power of attorney in Northern Ireland.

This is valid for a set period. It will end if someone becomes unable to make decisions for themselves. This means they no longer have mental capacity.

Power of attorney documents are created by the Office of the Public Guardian. You can apply online at **gov.uk/opg** or by phoning, emailing, or writing to the Office of the Public Guardian. If you have concerns or questions, you could seek legal advice from a solicitor.

Once the document is completed, it needs to be registered. This can be done online at **gov.uk/power-of-attorney**

There is a fee to register. But if you have a lower income or get benefits, you may not have to pay. Or the fee may be reduced.

Anyone can object to the power of attorney for 4 weeks after the application is made. After that time, it becomes valid. The document is sent to the person who applied, and the donor is informed.

The donor can cancel a power of attorney at any time while they are still able to make their own decisions (have mental capacity).

Making a will

A will is a legal document. It lets the person you look after record what they want to happen to their money, property and belongings (their estate) when they die. Depending on their situation, making a will can also make sure they do not pay too much inheritance tax. If they do not make a will, dealing with their estate can be a much longer process.

They can write it themselves, if they are able to, or a solicitor or will-writing service can do it for them. If their estate is more complicated, it might be best to get legal advice.

The will needs to be signed and witnessed to make it legal and valid. If it needs to be changed or updated, they need to do this officially by adding a codicil. Or they need to write a new will.

Some charities, including Macmillan, offer a free will-writing service. We have more information about writing a will and inheritance tax at **macmillan.org.uk/writing-a-will**

Making difficult decisions

There may come a time when the person you look after cannot make decisions for themselves. If you have power of attorney, you may be involved in making decisions for them. Or their healthcare team may involve you in decisions about their treatment and care.

This could include decisions about stopping treatment, or whether the person should have life-sustaining treatment or be resuscitated.

If the person has made an advance statement or advance decision to refuse treatment (page 90), you might already know their views and wishes. Or you may have already had conversations with them that will help you make difficult decisions. You might have made your own notes about what they want to happen. This will help remind everyone what was said and avoids any mistakes.

Sometimes it can be difficult to make decisions because other people also want to be involved. Or you may not want to be involved in making decisions at all. Use your own judgement and rely on the trust between you and the person you are caring for.

It is important to talk to any family members or friends who are involved in the person's care, to make sure you all agree. It also helps to have an honest conversation with the health and social care professionals involved. They can offer information and advice to help you make decisions. It is important you fully understand what each option is, and how a decision will affect the person you are caring for.

There may be times when the person's wishes cannot be met. For example, it may not be possible for them to stay at home until the end of their life. Sometimes it might be more comfortable for them to be in a hospice or hospital, where they can have specialist care and support.

This may be because their symptoms have become too difficult to manage at home. It can also be because it has become very tiring and difficult for you to care for the person at home. The GP or palliative care team can talk to them, and help them understand why their wishes cannot be met.

Although it can be disappointing, it is important to know that you have done your best. It does not need to be the end of your caring role. You can still visit and be closely involved in their care.

If a hospice is involved in caring for the person, the staff will support you and offer advice. Hospices offer a range of services, and are not only for the end of life (page 85).

Work and money

Working while caring

It can be difficult to balance work or education and looking after someone. It can be busy or stressful to stay in, or go back, to work or education. But you may benefit from:

- meeting and socialising with others
- talking and getting support from friends and colleagues
- keeping your workplace identity
- getting paid and any other benefits that come with your job
- keeping up to date with training or study.

If you have a carer's assessment, talk about your plans for work or education and the support you might need to be able to carry on or go back (pages 37 and 38). The assessor may be able to arrange replacement care while you are away from the person you look after (page 30).

> **"I had to stop work immediately to care for my daughter, which has been the biggest challenge of my life. Fortunately, my employer granted me carer's leave and sick leave while Lucy was having treatment."**
>
> Helga, who cared for her daughter Lucy

They may have information about support for you starting or returning to work or education. These may include help with applying for jobs and courses or learning new skills.

If you are working or in education, talk to your manager, human resources (HR), or student support department about how they can help you. There are often policies and procedures for supporting carers.

You may learn new skills in your role as a carer too. You may be able to transfer these skills into work or education. You might want to think about supporting other people who become carers in the future. Some places have a carer's network you can join.

Caring and your rights at work

If you look after someone, the following laws to protect you from discrimination:

- the Equality Act 2010
- the Human Rights Act, and Section 75 of the Northern Ireland Act (in Northern Ireland).

In some situations, carers are also protected by other disability laws.

Everyone has certain legal rights at work. These are called statutory rights. But your contract may come with extra rights called contractual rights. You can find out if you have these extra rights by looking at your contract or letter of employment, or the HR policies where you work.

Everyone can ask for flexible working, and can make 2 requests during a 12-month period. This right applies from the first day of employment. This might help you balance work or education with caring.

Flexible working might mean working:

- from home
- part-time or job sharing with someone else
- in school term times only
- your usual number of hours over fewer days (compressed hours)
- flexible hours or shifts rather than set times each day (flexi-time)
- with different start and finish times (staggered hours).

Your employer may also offer other options, such as unpaid leave where your job is protected. This means that you can take unpaid time off from your job, knowing that you will be able to return to it.

Everyone has the right to time off for emergencies or unexpected matters involving the person they care for. This time is usually unpaid, unless your employer offers it as a contractual right.

Emergencies may include:

- unexpected problems with replacement care
- if the person you look after is injured or unwell.

Working after caring

When you are no longer looking after the person you care for, you might think about going back to work, education or volunteering.

Looking for a new job

When your caring role has ended, you might want to look for a new job. You will have gained practical and communication skills while you were caring. You may have been organising appointments, care, and services. These are valuable skills for work or education.

You could add this to your CV and job applications, and talk about it in interviews.

If you live in England, Scotland or Wales, you can contact your local Jobcentre Plus about work. Visit **gov.uk/contact-jobcentre-plus**

If you live in Northern Ireland, you can contact the Jobs and Benefits office (page 151).

Job sites run by the government could also help. Try:

- **gov.uk/find-a-job** in England, Scotland and Wales
- **jobapplyni.com** in Northern Ireland.

Networking websites such as LinkedIn can also be useful for tips and job searches.

Learning new skills

After caring, you may want to learn something new or refresh the skills you already have. Your local library, community centre or adult education centre may be able to find suitable courses in your area.

You could look for more information about courses at:

- **learndirect.com**
- Skills For Life – **skillsforlife.campaign.gov.uk**
- Skill Up (Northern Ireland) – **nidirect.gov.uk/skillup**

You can find out more about what jobs might be suitable for you and take a skills assessment at **nationalcareersservice.direct.gov.uk**

A skills assessment can help you:

- find out what interests you
- recognise your skills
- find out what jobs you can do with the skills you have.

Volunteering

Volunteering can be a great way to help others, meet new people and develop new skills. You might want to help at the hospital where the person you look after had treatment. You could also help at your local carers' centre or volunteer for a charity.

You might be interested in becoming a Macmillan Cancer Voice (page 145). This is a UK-wide network for people to use their experiences to improve cancer care. If you are interested in becoming a Cancer Voice or volunteering for Macmillan in other ways, you can search for a role at **macmillan.org.uk/volunteering**

Benefits and financial support

Cancer often means extra costs for you and the person you look after. This can include paying for travel to hospital, or higher food or heating bills. If you have to give up work or reduce your hours, you may not have as much money.

You and the person you look after may be able to get benefits or financial support.

We have more information on financial help for people affected by cancer, including carers, in our booklet **Help with the cost of cancer** (page 138). We also have information about help with the cost of living. Visit **macmillan.org.uk/cost-of-living**

You can also call our money advisers on **0808 808 00 00** to find out more about what benefits you may be able to get.

Carer's Allowance

Carer's Allowance is a weekly payment for people who care for someone at least 35 hours a week. You may be eligible if your income is below a certain level and the person you look after receives certain benefits. These include:

- Personal Independence Payment (PIP) – daily living part
- Disability Living Allowance (DLA) – middle or highest care rate
- Attendance Allowance.

Find out more about who can get Carer's Allowance on **gov.uk** or **nidirect.gov.uk**

If you live in Scotland, you may be eligible for an extra payment called Carer's Allowance supplement. This payment is made 2 times a year. You can find out more at **mygov.scot/carers-allowance-supplement**

Carer's Allowance is for the main person that cares for someone. Only 1 person can get it. If other people care for the person you look after, you may need to talk about who that is.

If you are receiving Universal Credit (UC), you might be entitled to the carer's element of UC, even if you do not qualify for Carer's Allowance. This can affect the benefits that the person you care for receives, so it is best to check the different parts of UC.

You can find out more at **gov.uk/universal-credit/what-youll-get**

Carer's Credit

If you are a carer for the person you look after for at least 20 hours a week, you may be able to get Carer's Credit.

This is not an actual payment. It is a National Insurance credit, so it helps fill the gaps in your National Insurance record. This protects your right to a state pension.

The person you look after must receive certain benefits. These include:

- Personal Independence Payment (PIP) – daily living part
- Disability Living Allowance (DLA) – middle or highest care rate
- Attendance Allowance.

Find out more about who can get Carer's Credit on **gov.uk** or **nidirect.gov.uk**

Other benefits

You and the person you look after may be able to get other benefits. These could include:

- Universal Credit – for people on a lower income, or unable to work.
- Personal Independence Payment (PIP) – for people with a long-term physical or mental health condition or disability, who have difficulty doing everyday tasks or moving around.

PIP is not means tested. This means you can still get PIP if you are working, have savings or getting other benefits.

There are 2 parts to PIP:

- Daily living is for people who need help with everyday tasks. This may include eating, drinking, preparing food, washing, dressing, reading, communicating, managing their medications, making decisions about money or being around other people.
- Mobility is for people who need help with getting around, leaving the house and getting somewhere on their own.

The person you look after may be eligible for 1 or both parts. It is assessed by the Department of Work and Pensions (DWP). They look at:

- whether you can do things safely
- how long it takes
- how your condition affects each task
- whether you need people or equipment to help you.

Find out about PIP at **gov.uk/pip** or **nidirect.gov.uk/articles/personal-independence-payment-pip** in Northern Ireland.

If you live in Scotland, you may need to apply for Adult Disability Payment (ADP) instead of PIP. You can find out more at **mygov.scot/adult-disability-payment**

You can speak to a Macmillan money adviser by calling the Macmillan Support Line on **0808 808 00 00**. They are specially trained to help you get benefits you might be entitled to.

Other organisations can also help you get the financial support you need. These include your local Citizens Advice (page 150), Advice NI (page 149) or Carers UK (page 145).

Other financial support

There may be other financial support to help you and the person you care for. You can talk to our money advisers by calling the Macmillan Support Line. They can talk to you about benefits and money worries.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line on **0808 808 00 00**.

Your local area may have welfare schemes that give grants and loans. Your local council or Macmillan Information and Support Centre should be able to tell you what help you can get in your area (page 141).

Help with travel costs

If the person you look after claims certain benefits or has a low income, they might be able to claim a refund on their hospital travel costs. This may include:

- bus or train fares
- petrol costs
- taxi fares.

Ask the health or care team for more information. They can often offer free or discounted parking to people having cancer treatment.

The person you look after may be entitled to a Blue Badge for their car. A Blue Badge allows you to park in disabled parking spaces. You can put it in your car when you take them out.

To apply for a Blue Badge in England, Scotland or Wales, visit **gov.uk** or contact your local council. In Northern Ireland, apply online at **nidirect.gov.uk** or call **0300 200 7818**.

We have more information in our booklet **Help with the cost of cancer**.

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

Emotional effects of caring

Your feelings

Looking after someone can be rewarding, but also very demanding. At times you may feel:

- frightened
- sad
- angry
- guilty
- lonely.

The person you look after may also have these feelings.

As a carer, you might feel you have to stay positive for the person you look after. But no-one can be positive all the time. It can be a positive thing to say you are feeling tired, worried, depressed, or angry. Then you can talk about it and get support to help you cope.

If you have a carer's assessment, it is good to share your feelings (page 37 to 38). Your assessor can talk to you about your emotions and how to look after yourself. They will have information about support services and therapies. There are often local support groups for carers. They may be able to help with transport and replacement care (respite) for the person you look after, so you can go to the group.

Feelings can be stronger at times of change. This might be when the person you look after is unwell or needs more help.

Things can change for you too. You may start, or go back to, work or education. There might be a change in your family situation or finances. You may feel unwell or need hospital treatment. Or you may feel you cannot keep up the level of care you have been giving.

It is important that you tell others. If they understand how you are feeling, they can help. People have different support networks. You may want to talk to a partner, family, friends, health or social care professionals, or a support group.

Fear

You may feel frightened or worried about the future. You may hide your feelings to avoid upsetting the person you look after. You might also feel you have lost control over your own life.

Talking about your fears and worries can help. You could write them down and talk about them with the cancer doctor, GP, district nurse or specialist nurse. Having more information about the cancer, and what to expect, may help you feel less worried and more in control.

> **"When Waheed was going through treatment, I didn't feel there was much time or space to connect with my feelings. I put all my effort into supporting my wife."**
>
> Anthony

Depression

You are likely to have times when you feel low. This could be when you are very tired or the person you are caring for is unwell. These low moods may not last long. Most people find they have good and bad days.

Caring may sometimes be so demanding that you become depressed. Symptoms of depression can include:

- feeling sad or numb for weeks or more
- finding it hard to enjoy things that you would usually
- sleeping problems and changes in eating habits
- having no motivation, difficulty concentrating or finding it hard to make decisions.

If you think you may be depressed, talk to your GP. There is support and effective treatments that can help you.

Anger and resentment

It is normal to feel angry if someone close to you has cancer. You may also feel angry because you do not have time to do things you enjoy. You may feel your life has been put on hold. Sometimes you may feel resentful that others cannot give you the help or support you need.

The person you look after may not appear to appreciate what you do. Or they might be angry and upset with the situation, and direct these feelings towards you. If this happens, talking about it openly when you are both less tired may help to stop things getting worse.

It is important to understand that feeling angry is normal. There are some things you can do to help deal with your anger:

- Take some deep breaths, and think about what has caused it.
- Go for a brisk walk – exercise can help with anger.
- Talk about it with a family member, friend, or another carer.
- Think about what happened and how it could have been different.
- Write about your anger – this can help release it.

Loneliness or isolation

It is not unusual to feel lonely or isolated when you are caring for someone. You may feel you do not have enough time to see friends, or friends may think you are too busy to meet.

Try to see other people, even if it is just once or twice a week. Accept offers of help to give yourself breaks. Keeping in touch with friends through regular phone calls or social media can help.

If you do not have anyone to talk to, contact a local or online support group.

Guilt

You may feel guilty because you would like to have a break from caring. You may feel that you are not a good enough carer. When people feel guilty, they try to hide their feelings and worries more. This can make it difficult for people to understand what you are going through. So it is important to talk to people close to you about how you feel.

The person you are caring for may also feel guilty about how their illness is affecting you and others.

> "I felt quite angry and got aggressive at times because I didn't know where to go. I didn't know who to tell about the feelings I had."

Ben, who cared for his mum

Talking about your feelings

Being honest about your feelings can help you feel less stressed and more in control. You may think you should ignore your own feelings and only think about the needs of the person you look after. But you both need support to help you cope.

Try to get the support and information you need early on to help you develop ways of coping. Talk to family members, friends or one of the health or social care professionals involved in the person's care. If your feelings are getting overwhelming or you feel depressed, it is important to get professional help.

Counselling

If you find it difficult to talk to people you know, or you do not have anyone to talk to, it may help to talk to a counsellor. They can help you explore your feelings and find ways of coping with them.

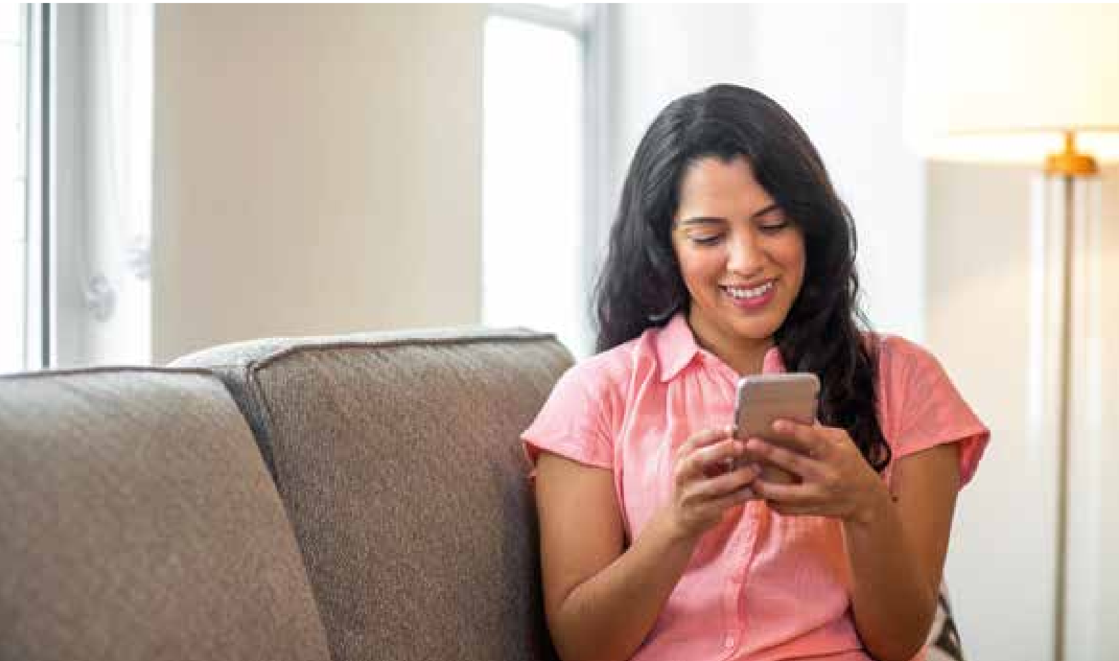
Your GP may refer you to a counsellor. Or your social worker, local support group or hospital information centre may be able to put you in contact with one. The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (page 148).

Support groups and online support

Support groups can be a good way to talk to other people in a similar situation. Many people find this very helpful. Some groups are specifically for carers. You can get information about support groups from your local council, GP surgery, the hospital or by searching online.

If you use the internet, you may want to join an online support group or chat room. They are easy to join, and you do not have to give your real name. Our Online Community has a specific group for carers (page 143).

Other organisations offer support to carers, such as Carers UK and Carers Trust (pages 144 and 145).



Looking after yourself

You need to look after yourself when you are caring for someone else. Taking the time to focus your own health and well-being will also benefit the person you look after.

If you have a carer's assessment, it is important to talk about your own wellbeing. The assessor can direct you to services that can help. They can also provide a one-off direct payment that you can use to do something for yourself. This might be going to exercise classes, or a holiday.

Take care of your health

- Tell your GP that you are a carer so they can give you support and advice.
- Go to your health and screening appointments.
- You might be able to have a free flu vaccination (jab) if you are the main carer.
- If you are having problems eating or sleeping, are struggling with difficult feelings or finding it hard to cope, talk to your GP.

Take regular breaks

- Accept help from others or ask for help.
- Make sure you have time off to relax.
- Do something you enjoy, like reading, going for a walk, meeting friends, or going for a meal.

Eat well

- Try to eat healthy food and sit down to eat a cooked meal.
- If you are tired, ask a family member or friend to help make meals in advance.
- Eat with a friend, or go out for dinner together.

Be active

- Try to get out of the house every day and do some gentle exercise, like walking. This can help you feel less tired and stressed.
- If you enjoy sport or going to the gym, try to keep doing this.

> **"Once I started running, I found that I was good at it and it gave me time to think. When it was a bad time, I would get my shoes on and go out. And I always came back feeling better."**
>
> Emma, who cared for her mum

Try to relax

- Try relaxation techniques using simple breathing and relaxation exercises. You can use apps, podcasts or CDs to guide you (available at your local library, or online). Or ask a healthcare professional for advice.
- Try having a massage or another complementary therapy that you enjoy. Your local Carers' Centre, Macmillan Information and Support Centre (page 141), or cancer support group may offer free complementary therapies for carers.

Get enough sleep

If you are looking after someone who is very ill, getting enough sleep can be difficult. You may not feel able to relax, or you may need to help them during the night. Try using relaxation techniques to help.

Some social services have care workers who can help at night. Your local social services or the Carers Trust will be able to tell you what is available in your area (page 144).

Relationships

You and the person you look after

Becoming a carer can affect your relationship with the person you look after. It may make the relationship stronger. You may also feel it changes your relationship. For example, if you are looking after a parent, you may feel your roles have been reversed. You may miss the relationship you had before. But it can also give you a chance to become closer to the person.

If your relationship with the person you are caring for was difficult before, it may become worse. Getting help and having time to yourself can make this easier. It is normal for both of you to have difficult feelings.

> **"I do appreciate mine and my mum's time a lot more now. I appreciate her more as a person. We've gotten a lot closer. We've got a better understanding of each other as well."**
>
> Ben, who cared for his mum

You may not feel sure about how to comfort the person you are caring for. Listening to them can be enough. You do not need to have all the answers.

All relationships are different. But these tips might help your relationship with the person you are caring for:

- Give yourselves time to get used to the change in your roles and talk about the changes.
- Try to be honest with each other about your feelings. Listen to each other's needs and find ways to meet them.
- Set boundaries to help each of you keep your independence and feel in control.
- Make sure the person you are caring for knows they are still in control. It is important they know they always have a choice in decisions that affect them.
- Keep to daily routines to give you both a sense of structure.
- Do not be afraid to be yourself, or to use laughter and humour in the right situations. Try to do things together that are fun. Laughing together can make you both feel less stressed.

Caring for a partner

Caring for your partner can affect your relationship. For example, you might have to take on a different role. Sometimes your future plans may change.

These tips might help if you are caring for your partner:

- Let your partner take as much responsibility as they can for their care, family issues, finances, and other decisions.
- Talk about things together to help you to understand what the other person wants.
- If you need help with your relationship, you may find it helpful to talk to a professional, such as a counsellor.
- If you have children and need help with talking to them, specialist nurses, such as Macmillan nurses, can support you with this.

Your sex life

Your sex life may be affected by your partner having cancer. Cancer and cancer treatments can cause changes that are:

- physical – they may have side effects or symptoms that change how their body works or looks
- emotional – you may both be dealing with stress, worry and other difficult feelings
- practical – your usual routines and roles may have changed.

You may feel more tired or less in control of your life. Your role may have changed within the home and at work.

You may feel the intimacy you and your partner had before the diagnosis has been replaced by your caring role. You may find it difficult to be a carer for your partner and think about them sexually. Or sex may still be something that makes things feel like they did before. Talking openly with your partner can help you both feel closer.

There are different ways to show your partner you care about them. You can show it through touching, such as holding hands or massages.

Doctors and nurses are used to talking about issues like sex. They can give you advice on how your sex life may be affected. They can also give you information about things that may help. We have more information in our booklet **Cancer and your sex life** (page 138).

If you identify as LGBTQ+

If you identify as LGBTQ+, you may worry about being treated differently by your partner's healthcare team.

The healthcare team are there to support you both and treat you in a way you both feel comfortable with.

You may worry about being treated less well. This may be because you have had difficult or negative experiences before.

You may both worry about:

- not getting the right information or support for your sexual and romantic orientation and your sexual activity
- healthcare professionals making assumptions about sexual and romantic orientation or gender identity
- a partner being mistaken for a friend or family member
- being ignored.

But telling the team about your relationship, and them recognising it, might make you both feel more supported. We have more information about LGBTQ+ cancer care at **macmillan.org.uk/lgbtq**

OUTpatients also offers support for LGBTQ+ people affected by cancer (page 155).

Your relationship with others

Being a carer can also affect your relationship with other people around you.

Family

If you are the main carer for someone with cancer, talking to other family members may help you cope. It may also bring you closer. But sometimes family relationships change.

Some family members may want to talk about their feelings and what is happening. Others may not. They might find this difficult, even when decisions need to be made. If things are already difficult, they might get worse because of the stress. If there are problems, speak to a health professional or social worker who is involved.

If you are the main carer, other family members may ask you for updates on how the person is. This can be stressful for you. It can be hard to deal with how they react. Try to ask other family members to share updates to the wider family by email or text.

If there are children or teenagers in the family, it may be the first time they have dealt with a serious illness.

We have more information in our booklets **Cancer and relationships: Support for partners, families and friends** and **Talking with someone who has cancer** (page 138).

Your partner

Your partner can be an important source of support for you. Your caring role may affect your relationship with your partner:

- You may have less time to spend together.
- Your sex life may be affected because you are both tired.
- Your finances may be affected, and this can cause worry.

Try to talk honestly with your partner about any worries you have.

If money is a worry, Macmillan money advisers can help (page 141).

> **"The nurse helped us decide the best way to talk to our young children about the condition, and explain it in a way they would understand."**
>
> Anthony

Friends

Friends may be able to give you practical and emotional support. But you may see them less often because of your caring commitments. They may not contact you as much because they are worried about what to say.

Try talking to them honestly about being a carer. This can help them understand your situation and how you feel. Using social media is also a good way of talking to friends.

> **"My friends drifted away. They still call me once a month or so, but I can't go out any more. I don't think they realise how full-on my life is now."**
>
> Amy, who cared for her dad

Other support

There are other ways of getting support. You may not have family and friends who can support you. Talk to the health and social care professionals involved in the person's care. They can help you get the support you need. You can also get support from other places:

- Carers UK or the Carers Trust can give you information and advice (pages 144 and 145).
- You could join a self-help and support group and speak to other carers or other people affected by cancer.
- You can talk to other carers through our Online Community at **macmillan.org.uk/carersgroup**
- You can also call our cancer support specialists on **0800 808 00 00** for information and emotional support.
- Cancer Caring Coping is a website where you can read about how other carers looking after a person with cancer have coped (page 144). It also has information about what they have found helpful.

End of life and bereavement

Caring for someone at the end of life

Many people with cancer get better and recover from treatment. But sadly, some people do not. Caring for someone with advanced cancer or who is dying can be challenging. It can be difficult for you, and the person you are caring for, to come to terms with.

Caring for someone who is dying is an upsetting and emotional time. You are likely to need extra help and support from family members, friends, or professionals.

You may want more information about what to expect when someone dies. You could talk about this with the doctors or nurses involved. Palliative care nurses and doctors are used to talking about these issues.

We have more information in our booklet **A guide for the end of life** (page 138) which might help you plan for this time. This may be helpful for you and the person you are caring for.

You may also find support and information on the Dying Matters website, run by Hospice UK (page 156). The website is for people nearing the end of their life. It also has information for carers, family and friends. The information and support section has information for carers on:

- what happens at the end of life
- talking to someone about dying
- what to do after a death
- coping with a bereavement.

> "My mum and I discussed her end-of-life wishes. I cannot imagine what would have happened if I had to make those decisions without those vital conversations to guide me."

Maymay, who cared for her mum

Coping with bereavement

Grieving does not always start when the person you look after dies. You may have already been missing the relationship you had and the things you shared with them.

After the death of the person you looked after, and for some time afterwards, it is normal to feel different emotions including:

- numbness and disbelief
- anger
- anxiety
- distress
- sadness
- loneliness.

You may also have a sense of relief that the person is not suffering any more. Your thoughts and feelings will vary. Sometimes they may be very intense and stop you doing things. At other times they may be in the background, and you will still be able to do your day-to-day activities.

Everyone will experience grief at some point in their lives. But sometimes feelings can be very intense and difficult to deal with. You may want to talk to your family and friends about how you are feeling. Some people prefer to talk to someone they do not know.

Some people need extra help to manage their emotions.

There are organisations that can support you when you are bereaved, including Cruse Bereavement Care (page 157).

Your GP can provide support and may be able put you in contact with a local bereavement counsellor. Many hospices also provide bereavement support.

You can phone the Macmillan Support Line on **0808 808 00 00** for information about bereavement support. There are bereavement groups on our Online Community, which many people find helpful. Visit **macmillan.org.uk/bereavementgroups**

We also have more information in our booklet **After someone dies: coping with bereavement** (page 138).

> **"If you ever want to know you're not alone, all you have to do is sign up to the Macmillan Online community. There are so many people out there who feel the same."**
>
> Gary, diagnosed with mouth cancer

Further information

About our information

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

Order what you need

You may want to order more booklets or leaflets like this one.
Visit **orders.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
- interactive PDFs
- 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 **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and see the options and opening times.

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

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

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Support for carers

Cancer Caring Coping

www.cancercaringcoping.com
Shares stories and experiences of carers who want to give support, advice and tips on coping in the caring role. Has advice for carers on how to look after themselves.

Carers Direct Helpline

Helpline and webchat **0300 123 1053**
www.nhs.uk/carersdirect
Confidential information, advice and support for carers. Offers advice on getting a break from caring, assessments, financial support, and going to work.

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **0289 043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

The Respite Association

www.respiteassociation.org
Arranges short breaks for carers and funds respite care.

General cancer support organisations

Cancer Focus Northern Ireland

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

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

General health information

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
www.bladderandbowel.org
Information and support for anyone affected by bladder and bowel control problems as well as their families, carers and healthcare professionals.

Bladder and Bowel UK

www.bbuk.org.uk
Helpline **0161 214 4591**
Information and support on bladder and bowel health and anyone affect by bladder or bowel control problems.

Care Quality Commission

www.cqc.org.uk
Tel **0300 061 6161**
Independent regulator of health and adult social care in England.

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

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

NHS Inform

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

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

Citizens Advice

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

England

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

Scotland

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

Wales

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

Civil Legal Advice

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

Disability and Carers Service

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

GOV.UK

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

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Law Centres Network

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

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 123 3233**

Money Advice Scotland

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

NiDirect

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

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

Equipment and advice on living with a disability

British Red Cross

Helpline **0808 196 3651**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

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

Living Made Easy

Helpline **0300 999 0004**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Motability Scheme

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

Scope

Helpline **0808 800 3333**
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK

Helpline **0800 678 1602**
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**
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.

OUTpatients

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

Advanced cancer and end-of-life care

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline **0196271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Hope Again

Helpline **0808 808 1677**
www.hopeagain.org.uk
Designed for young people by young people, Hope Again is part of Cruse Bereavement Care. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

Widowed and Young (WAY)

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

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

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

With thanks to: Diana Borthwick, Clinical Nurse Specialist; Ben Bowers, Community Palliative Care Nurse/Community Research Nurse Consultant; Karen Clayton, Clinical Nurse Specialist; Dr Denis Colligan, GP; Dr Anthony Cunliffe, GP; Jennifer Fulton, Physiotherapist; Nikki Hunter, Clinical Nurse Specialist; Diane Jones, Physiotherapist; Dr Pauline Love, GP; and Hannah Wylie, Occupational Therapist.

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 **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about looking after someone with cancer. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

National Institute for Health and Care Excellence Supporting adult carers committee. Supporting Adult Carers: NICE guideline [NG150]. 2020. Available from www.nice.org.uk/guidance/ng150 [accessed May 2022].

National Institute for Health and Care Excellence People's experience in adult social care services committee. People's experience in adult social care services: improving the experience of care and support for people using adult social care services: NICE guideline [NG86]. 2018. Available from www.nice.org.uk/guidance/ng86 [accessed May 2022].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping.
   Or just a cup of tea and a chat. Could you lend a hand?

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from
☐☐ ☐☐

Expiry date
☐☐ ☐☐

Issue no
☐☐☐

Security number
☐☐☐

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about looking after someone who has cancer. It is for anyone who gives unpaid support to someone who could not manage without this help.

This booklet is for adult carers. We have separate information for young carers under the age of 18.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use.

Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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