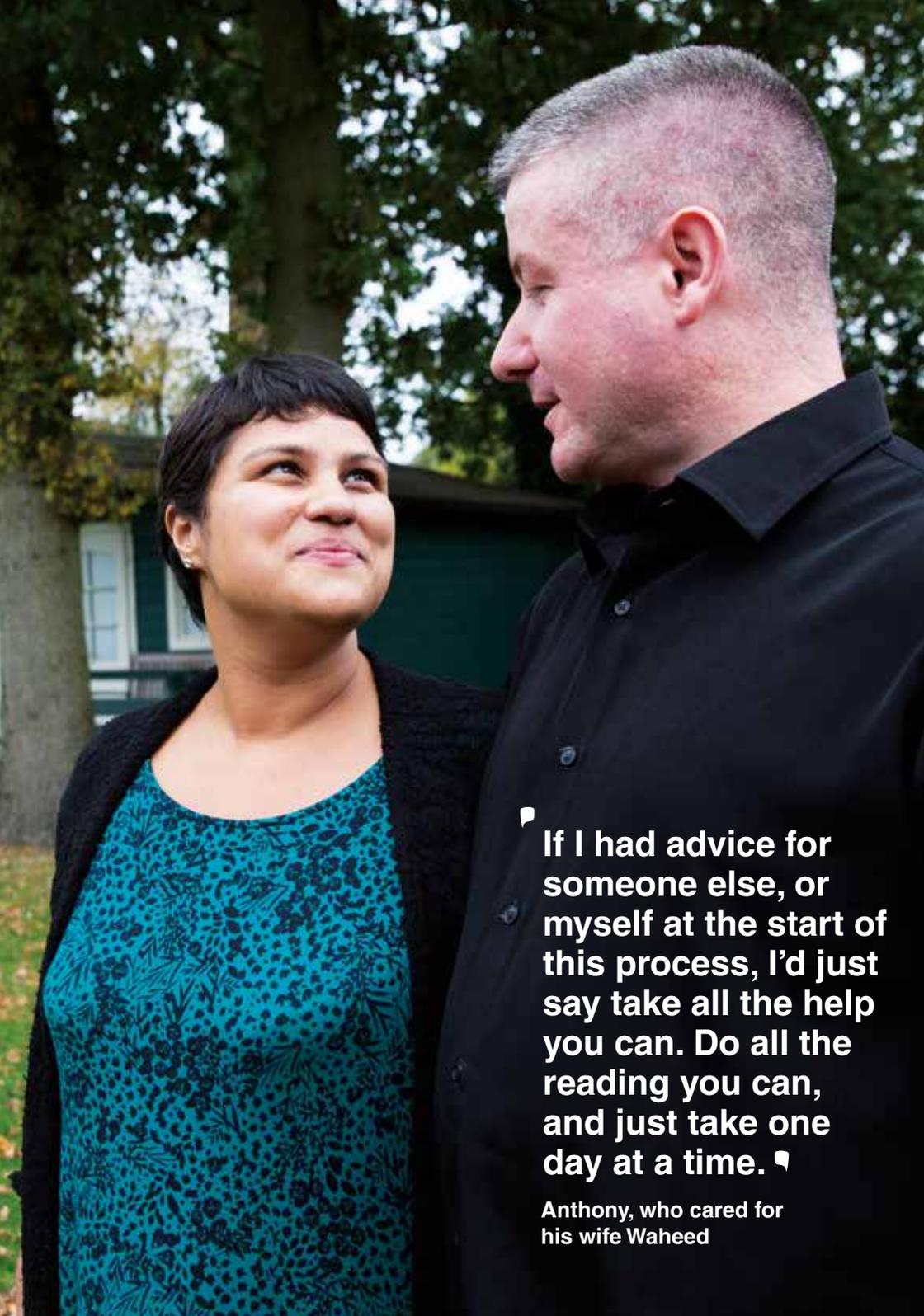


MACMILLAN
CANCER SUPPORT

LOOKING AFTER SOMEONE WITH CANCER





If I had advice for someone else, or myself at the start of this process, I'd just say take all the help you can. Do all the reading you can, and just take one day at a time. 🗨

Anthony, who cared for his wife Waheed

About this booklet

This booklet is about looking after someone who has cancer.

It explains:

- what it means to be a carer
- who can help support you and the person you are caring for
- the practical, emotional and financial issues you may face, and how to cope with them
- ways you can help the person you are caring for manage symptoms or side effects
- how to look after yourself.

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

This booklet is for adult carers. We have another booklet for young carers under the age of 18 called **A guide for young people looking after someone with cancer** (see page 114).

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 118 to 125, there are details of other organisations that can help.

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. Anthony cared for his wife Waheed when she was diagnosed with cancer. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

For more information

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

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

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

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

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AM I A CARER?

What is a carer?

6

What is a carer?

You may not see yourself as a carer. You may think you are just helping out. Recognising you are a carer can be an important step in getting the 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. This includes a partner, family member, friend or neighbour.

Being a carer for someone can mean:

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

Every caring situation is different. Your responsibilities will depend on what the person needs and what you are able to offer. You may be sharing 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. You might have a lot of different feelings, such as sadness, anger, guilt and loneliness (see pages 88 to 92). Getting support and having someone you can talk to about how you feel might help you cope.

Different health and social care professionals will support you as a carer (see pages 12 to 19). There are also organisations that can help (see pages 118 to 125).

If you are the main carer for a person with cancer, you can have an assessment of your needs. This is called a carer's assessment (see pages 22 to 23). It is done by social services. The assessment may help you to get practical support.

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 (see pages 95 to 97). You may have to balance caring with other things, such as working (see pages 78 to 79) and other relationships (see pages 104 to 105). As a carer you may also need financial support (see pages 82 to 85). You may also be able to get different benefits for carers.

If you are aged under 18 and looking after someone with cancer, you are a young carer. We have separate information for young carers in our booklet **A guide for young people looking after someone with cancer** (see page 114).

'I never thought of myself as a carer. I was just being a daughter, looking after my dad.'

Victoria, who cared for her dad



WHO CAN HELP?

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Support from health and social care professionals

You may be in contact with different health and social care professionals. This is because the person you are caring for might have different needs. These professionals can support you as a carer. They can give you advice and direct you to different services that can help.

There may be a main person for you to contact at the hospital called a key worker. You can contact them if there are problems. They may be a specialist nurse or social worker.

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

- a surgeon – who is a specialist in treating cancer with surgery
- a cancer doctor (oncologist) – who is a specialist in cancer treatments
- specialist nurses – who can give you information and support.

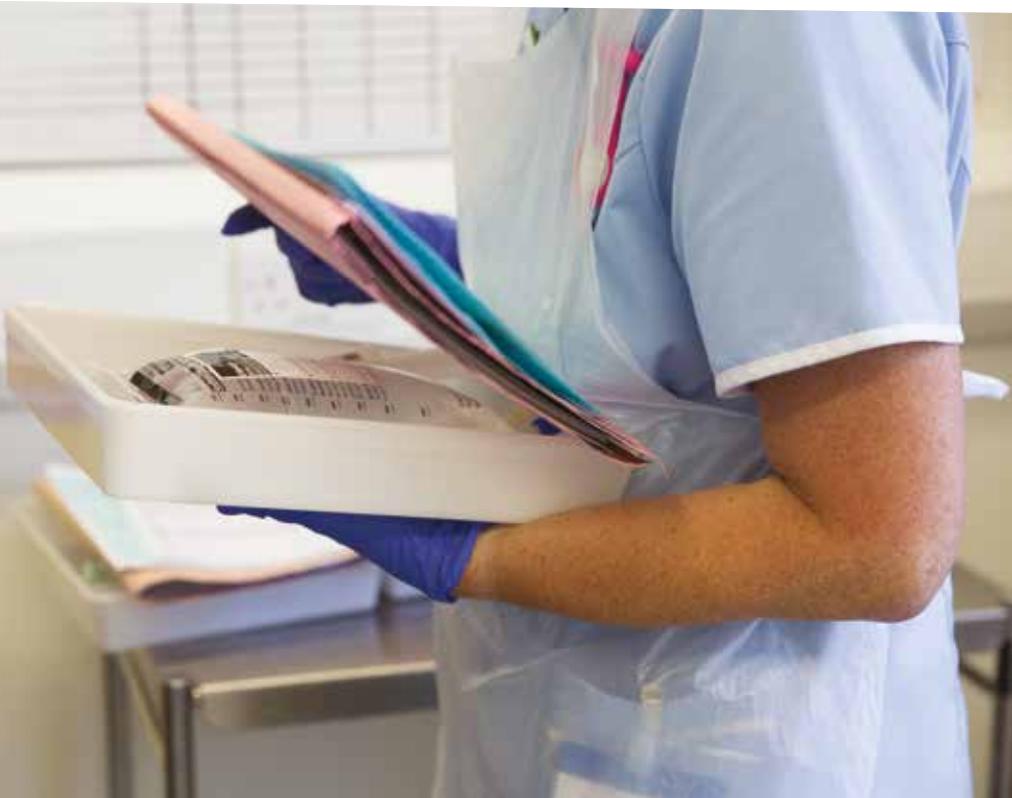
At other times you may also meet:

- a GP – who is responsible for the healthcare of the person you are caring for at home
- district nurses – who support people at home
- social workers – who assess the practical and social help you or the person you are caring for needs
- physiotherapists – who give advice to help improve body movement (mobility)

- a dietitian – who gives advice on nutrition and problems with eating
- occupational therapists – who help people who are having problems doing everyday tasks.

It helps to write down the names and contact details of the professionals you meet, in case you need to contact them.

Healthcare 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, specialist nurse or GP.



Talking to healthcare professionals

Talking to doctors, nurses and other healthcare professionals can feel overwhelming. But as a carer, 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 the wellbeing of person you are caring for. It also helps you to feel more supported.

You might go to hospital appointments with the person you are caring for. Here are some tips to help you get the most from appointments:

- Before you go to the appointment, talk to the person you are caring for about questions they want to ask.
- Write notes during the appointment to help you remember what is said.
- Ask healthcare professionals to explain anything you do not understand.
- If there are things the healthcare professional cannot help with, ask who you should contact.

As a carer, try to be honest with healthcare professionals about what is happening. This is so they can give you the right support. This does not mean you need to speak instead of the person you are caring for at appointments. But make sure you tell the healthcare professional anything that is helpful. For example, you could tell them your opinion on how well you think a new medicine is controlling a symptom.

You can also ask for advice and support about caring. Healthcare professionals understand that you need support too.

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

Anthony, who cared for his wife Waheed

Care plans

Everyone with a long-term condition should have a care plan if they want one. A care plan is an agreement between the person who is ill and health or social care professionals. It lists the services they will get after treatment or after leaving hospital. It also includes information about what they can do to manage their day-to-day health.

Ask the key worker, specialist nurse or social worker if a care plan has been organised. Make sure you understand everything in the care plan. If you do not, ask if they can explain it to you or give a different example. If the person you are caring for is offered help with personal care, ask whether you have to pay for it. These services are not always free.

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 (local doctor)

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

Tell the GP of the person you are caring for as soon as possible that you are looking after them. They can help you by:

- giving you information about NHS services (see page 120), social services and voluntary services
- advising you about the person's condition and supporting you so you feel more confident about looking after them
- providing supporting letters and information for benefits (such as Attendance Allowance), your local housing department or blue badge scheme (see page 85).

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

Contacting the GP

You may need to see the GP if the person you are caring for has a new symptom or is unwell. If they are having cancer treatment, you may have been asked to contact a 24-hospital number. You can also call their key worker. It is very important to follow the advice you have been given by their hospital team.

Contact the GP, hospital or key worker straight away if the condition of the person you are caring for seems to be getting worse. 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. You should write down the details of your out-of-hours service, along with other important contact details.

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

District and community nurses

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

A district nurse or a community nurse will assess the healthcare needs of the person you are caring for. Community nurses work with district nurses to care for people at home.

The district nurse can:

- support you and the person you are caring for, 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 are caring for are happy with this
- give injections, change wound dressings or remove stitches
- help with managing stomas, catheters, feeding tubes and central lines
- give advice on eating well (nutrition), looking after skin and pressure areas, bowel or bladder problems
- refer you or the person you are caring for to other health or social care professionals you may need.

The district nurse can also arrange equipment to be delivered (see pages 34 to 36). They will show you and the person you are caring for how to use it safely.

Palliative care team

The person you are caring for may need specialist help with symptoms caused by the cancer, such as pain. Your GP, hospital doctor, nurse or keyworker can refer you to a community palliative care team.

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

We have more information about controlling cancer symptoms in our booklet **Managing the symptoms of cancer** (see page 114).

Macmillan nurse

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

Marie Curie nurse

Marie Curie nurses provide free nursing care, usually during the last weeks of someone's life. 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 can check the standards of care in nursing agencies. Visit cqc.org.uk for more information.

Physiotherapist

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

OTs can look at how the person you are caring for manages day-to-day activities. They can suggest and arrange practical changes to make a home safe, comfortable and easy to live in.

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

The person you are caring for might need adaptations, aids or equipment to help them at home. OTs can give them information about things that might be right for them. The OT can arrange any adaptations, aids or equipment the person needs.

A social worker or district nurse can usually arrange for an OT to visit.

Pharmacist

Your local pharmacist can give you information to help you understand the medicines the person you are caring for is prescribed. They can also tell you about things to help with giving the person their medicine. For example, they can explain about pill organisers (dispensers) and pill timers. You may see a pharmacist at the hospital or in your local chemist. Some pharmacists may arrange for medicines to be delivered to the home.

Psychologist or counsellor

There are different professionals who can support the person you are caring for if they have difficult feelings. As a carer, you may also need professional support to help manage feelings of anxiety, low mood or depression (see pages 88 to 92). If you have any of these feelings it is important to talk to your GP. They may be able to refer you to a psychologist or counsellor for expert emotional support.

Continence adviser

Your district nurse will give you advice if the person you are caring for has problems with leakage (incontinence) from their bladder or bowel. They can also arrange for a referral to a clinic to see a continence adviser. They assess the problem and give you advice and information about aids to manage continence problems. You may also be able to get help with laundry services (see page 25). You can get more information from the Bladder and Bowel Community – visit bladderandbowel.org



Help from social services

There are many ways social services can help you and the person you are caring for. They can offer practical and emotional support.

Social workers

A social worker can assess the practical and social help you and the person with cancer need. They are also trained in counselling and giving emotional support. Some social workers are based in hospitals or in 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 social care needs assessment

Before the person you are caring for can get help, they need a social care needs assessment. You can contact social services at your local council and ask for a needs assessment. You can call them, or do it online.

A social worker or occupational therapist can visit the person you are caring for at home to do the assessment. Sometimes they do it by phone. They ask the person how they manage everyday activities, like washing, dressing and cooking. A separate assessment of the home might be needed.

It is important the person you are caring for gives as much information as possible. It may help to talk about everyday activities and write down things that are difficult. You should do this before the assessment. If the person you are caring for finds talking difficult, you can speak on their behalf. You can also take notes during the assessment.

You usually get the results of the assessment in a week. Help can be provided by social services or arranged with other organisations such as charities. The services they may provide include:

- someone to sit with the person you are caring for, to give you some time for yourself (sitting services – see page 61)
- meals at home (meals on wheels)
- a laundry service for people with incontinence
- equipment and adaptations to the home (see pages 34 to 37)
- benefits advice (see pages 82 to 85)
- respite care for the person you are caring for, to give you a break from caring responsibilities (see pages 60 to 62).

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

You may be able to get NHS Continuing Health Care (CHC) if the person you are caring for needs lots of ongoing care in their own home. Ask a health or social care professional how to apply for this.

Carer's assessment

If you are the main carer for a person with cancer, you can ask social services for an assessment of your needs to see what might help you. This is called a carer's assessment. You can have this even if the person you are caring for does not have their needs assessed or does not qualify for support.

The person doing the assessment will ask how you are coping with caring. This includes the effects on your physical and emotional health, work and relationships. Be as honest as possible with them. You can have someone there with you for support.

After the assessment, social services will write to you to tell you if you qualify for support. If you do they will explain how they 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 able to get benefits because you are a carer (see pages 82 to 85).

You may be able to get direct payments from the council. This means they give you money to organise care services yourself. Ask your local council for more information about direct payments. You can also visit **gov.uk** or the NHS website at **nhs.uk**

'I wasn't identified as a carer or offered a carer's assessment. I think because I seemed confident and went into meetings with a long list of questions and a notebook to carefully write everything down, people thought I was in control. I didn't really see myself as a carer so didn't try to access any support that might be available to carers.'

Emma, who cared for her mum

Home care service

You may get help from care workers to support you and the person you are caring for (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 social services or the Carers Trust can tell you what is available in your area (see page 118).

If you need help with cleaning your home, 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. Agencies can be expensive, so it is a good idea to compare a few, to find the best price.

Meals at home service

It may be possible for the person you are caring for to have meals provided at home (sometimes called meals on wheels). This service usually has to be paid for. It may be provided by a private company or the local authority.

The organisations offer different meals that can be made to suit a person's cultural and religious needs or special dietary needs. The meals are frozen, so they can go in the freezer to eat later. Daily hot meals are usually only provided if the person cannot manage the frozen meals service.

A social worker can arrange meals on wheels.

Visit [gov.uk/meals-home](https://www.gov.uk/meals-home) to see what services they can provide.

Laundry service

If you are caring for someone who has problems with incontinence, your local social services department may be able to provide a laundry service. Or you may be able to get a grant for laundry costs. Ask the district nurse, GP or social worker about this.

Help from family and friends

It is a good idea to think about the kind of help you might need. This could be from family members, friends or a local support group. It is important you know who you can ask for help and what they could do.

Having a good support network can make a big difference. Asking others for help is often the most sensible thing to do and is not a sign of failing. Try to talk openly with people about your role as a carer and the help you need. You do not have to protect others in your family by doing it all by yourself.

Sharing the caring responsibilities with family and friends means that you have time to look after yourself, as well as the person you are caring for. It also helps family and friends understand the situation better and give you support.

Some people may offer to help. Other people may not know how to ask, or what to do. Or they may not realise how much help you need.

Getting help from other people also benefits the person you are caring for. It gives them the chance to spend time with others. It can also help make them feel well supported. They may be relieved that you are getting the support you need. Make sure you involve the person you are caring for. Try to agree together on who does what.

You can start by:

- making a list of day-to-day 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 and talking or listening, so you can have a break
- taking the person you are caring for out
- taking the person you are caring for to GP or hospital appointments
- helping you with the person's personal care or bedtime routines.

Make sure anyone who looks after the person for you all the information they need. This could include what the person you are caring for likes to eat, or information about the medicines they take. It is also important to make sure they have important phone numbers of who to contact in case of problems.

Family members may not do things the same way as you do. You can make suggestions, but it is important to trust them.

Using a rota

Sometimes it is helpful to have 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 it can also be helpful if you do. It can help make the best use of everyone's time. We have included examples of things you could add to the rota. You could copy the table and use it for different weeks.

Monday	8am: Saffiyah taking the kids to school	Saffiyah's phone number:
Tuesday	1pm: Pat driving to day unit for chemotherapy	Pat's phone number: Phone number for day unit:
Wednesday	8am: Saffiyah taking the kids to school	
Thursday	7pm: Stu calling physiotherapist to ask about exercises	Stu's phone number: Physiotherapist's phone number:
Friday	5pm: Keisha cooking dinner	Keisha's phone number:
Saturday	10am: Pat doing the ironing	
Sunday	4pm: Liz visiting	Liz's phone number:

Carers UK also has a free online and mobile app called **Jointly**, which you could use to co-ordinate who is doing what. For more information, visit carersuk.org





CARING AT HOME

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Organising help and services

If the person you are caring for is in hospital help and services will usually be organised before they come home. At home, the district nurses, social worker or occupational therapist can usually arrange more help if it is needed.

Before coming home or at the end of treatment, the person you are caring for may have a holistic needs assessment. Their key worker asks questions about how they are feeling and the help they need (see pages 10 to 19). They create a care plan together. This will include ideas to help them feel less worried. It will also include contact details for helpful organisations or services. You can go to this meeting if the person you look after would like you to be there.

Everyone involved in the person's care should have a copy of the care plan, including the GP.

We have more information about the holistic needs assessment in our booklet **Holistic needs assessment: planning your care and support** (see page 114).

Going home

If there are a lot of things to talk about before leaving the hospital, the ward nurses or the person's key worker may arrange a meeting. They may invite:

- the person with cancer and you as their main carer
- the cancer doctor in charge of their care
- specialist nurses
- an occupational therapist (OT – see pages 18 to 19)
- a social worker (see pages 21 to 23).

If you are the main carer, you should tell the healthcare team. It is important your opinions are listened to. You should be a part of discussions about discharge and the plans for going home. The right help and support should be in place before the person you are caring for goes home. Talk to the healthcare team if there is anything you are not happy with. They can refer you to see a social worker who can arrange a carers assessment (see pages 21 to 23).

You may feel worried about what will happen when they go home. You may feel worried about how you will cope. Sometimes the person leaving hospital can involve big changes for both of you. This could be if the person is coming to stay with you. It is important to talk to the healthcare team about your needs and concerns. If you find it difficult to talk to them, it might help to have someone else with you. This will help you get the support you need. There are different people and support organisations that can help.

The person you are caring for should have a care plan or discharge information to take home. This should explain their medicines, any special diet they need and where to get more information they give you. Always ask about anything support. Make sure you understand the you do not understand.

Our booklet **Going home from hospital** has more information about the discharge information you might need (see page 114).

Equipment and changes to the home

Aids or equipment can help make things easier for the person you are caring for. It can also help make life easier for you as a carer. There are also changes to the home that might help.

Some equipment is provided by the local social services. The NHS also provides some healthcare equipment. A hospital or hospice can also supply equipment before a person goes home.

If the person you are caring for might need adaptations or equipment, a hospital occupational therapist (OT – see pages 18 to 19) will assess them before they go home. This can help you understand what equipment might help. The OT can give expert advice on what might be suitable for the person and for your needs. Ask the GP, social worker or district nurse to refer you, or contact your local council for an OT assessment.

You can also buy or hire some types of equipment from:

- your local pharmacy – you can also ask your pharmacist about local suppliers
- medical equipment shops
- voluntary organisations and charities, such as the British Red Cross (see pages 123 to 124).

A nurse, OT or physiotherapist will show you how to use equipment safely. They can also tell you where to position or store it.

Carers UK has a list of equipment and adaptations you may find helpful (see page 118). The Disabled Living Foundation also has useful information (see page 124). Some people may be able to get a Macmillan grant to help pay for equipment (see page 117).

Types of equipment

Wheelchairs and walking aids

If the person you are caring for has difficulty walking, using a walking stick, walking frame or sometimes a wheelchair can be helpful. The district nurse, an OT or a member of the healthcare team can arrange this (see pages 10 to 19).

Beds and chairs

If the person you are caring for needs to spend 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 heighten a bed (bed raisers)
- a hospital bed at home.

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

An OT or physiotherapist can give you advice on the main chair that the person uses. They may be able to provide a more suitable chair, such as a recliner chair.

Commodes, bedpans and urinals

If the person you are caring for needs to use a commode, bedpan or urinal, the district nurse or OT should be able to arrange this. You can also buy these from pharmacies or medical equipment shops.

Bathing equipment

If the person you are caring for has difficulty having a shower or bath, a bath chair, board or shower stool may help. An OT or physiotherapist can assess their needs. They can talk to you both about what would work best for their situation.

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. This gives medicines as a vapour to inhale.

Other types of equipment

There are other, smaller pieces of equipment that could help the person you are caring for. These can include things like:

- 2-handled mugs
- specially adapted cutlery
- grab rails for areas like the bathroom.

Changes to the home

Certain changes to the home can make life easier and more comfortable for the person you are caring for. An OT can suggest and arrange small, practical changes to make a home safe, comfortable and easy 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.

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

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 you start any building work.



Organising their room

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

Here are some tips:

- Talk to them about which room they would prefer.
- If they have difficulties moving around, try to choose a room that is near a bathroom.
- Try to make sure you can get around both sides of the bed.
- Put a small table next to the bed, so they can keep personal things nearby.
- Ask if there is anything they would like in the room, such as a computer, TV, phone, pictures or photos.

Sleeping arrangements

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

Helpful technology

New technologies can help people living with cancer be more independent. They can also help you to feel more reassured. These technologies include the following:

- **Personal alarms.** By touching a button worn around the neck or wrist, the user can contact a 24-hour emergency response centre for help.
- **Telecare.** Sensors are placed around the home which identify if there is a gas leak or fire, or if the front door is open. They send an alert to someone in a monitoring centre.
- **Telehealth.** This can send information from equipment, such as heart or blood pressure monitors, to someone in a monitoring centre. They can then give the information to the person's GP or healthcare team. This can help check conditions such as asthma, heart failure, diabetes and high blood pressure.

'I use Telecare constantly. It's amazing. It means I can go out to work and know that he can get help.'

Sarifa, who cared for her husband and son

You can find out more about Telehealth and Telecare on the Carers UK website – visit [carersuk.org](https://www.carersuk.org)

There are also mobile apps to help carers. **My Organiser** is a free Macmillan app that helps you plan and record things. This includes appointment times, contact details and when to take medicines. See page 117 for more information. Search for 'My Organiser' on the Apple App Store or Google Play on your phone.

Jointly is an app that can help you be organised and feel supported as a carer. You can get more information from Carers UK (see page 118).



Managing everyday needs

The person you are caring for may feel weak or tired because of their symptoms or treatment side effects. How much you do and what care you provide may change over time. You may start to do less if they have finished treatment and are recovering. If the cancer becomes more advanced, you may decide to do more. This depends on your situation.

As a carer, you can get support from different health and social care professionals (see pages 10 to 19). You can also ask family and friends for help (see pages 26 to 28). Or contact support organisations (see pages 118 to 125).

Some of the things you may need to do as a carer may make you or the the person you care for feel uncomfortable. Talk to a health professional or social worker if this happens. They may be able to arrange for other services to help you.

'My role as a carer was sometimes to help Katy walk, dress and get into the wheelchair. I also did household jobs, so it's a full-time job. You end up doing many roles as a carer. It's a huge learning curve.'

Ciarán, who cared for his wife Katy

Washing and bathing

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

If you prefer to do it yourself, they can show you how. 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 and the floor is not wet.
- Be sensitive and protect their dignity.
- Allow them to safely do what they can.

Clothing

Some people prefer to wear the clothes they have always worn. It can help them feel more like themselves. But sometimes other clothes may be more suitable.

Tips for clothing

- Loose clothes may feel more comfortable.
- Skirts or trousers with elastic waistbands can be easier to get on and off.
- Layers that can easily be taken off and put back on are a good idea if they feel hot or cold easily.
- 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.

Try using a plastic hair-washing tray if they cannot get out of bed easily. 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.

We have more information about hair loss caused by cancer treatment in our booklet **Coping with hair loss** (see page 114).

Nail care

Some treatments affect a person's nails and make them more brittle. We have more information about looking after nails. The nurses at the hospital clinic can also give you advice. Chiropodists or podiatrists who help treat foot problems can 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.

Toilet needs

If the person you are caring for needs help to go to the toilet, try to have their bedroom close to it. Ask the district nurse for a commode, bedpan or urinal to keep nearby. Social services can provide aids, such as a raised toilet seat, commode or hand rails (see pages 32 to 37).

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, pads or pants. They can also usually arrange a referral to a continence adviser. Social services may be able to provide laundry services (see page 25).

Standing and walking

The person you are caring for may need your help to stand or walk. Ask a physiotherapist 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 give you information about how to prevent a fall.

Tips on standing and walking

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

If the person has a fall, do not move them. This is because you could hurt them or yourself by doing this. Contact the GP or district nurses for advice, or in an emergency call an ambulance.

A personal alarm may be a good idea if the person you are caring for is on their own some of the time. It allows them to call for help by pressing a button worn around their neck or wrist to alert a 24-hour response centre (see page 40). The staff at the centre then send the best person to help.

A bed or chair sensor can detect if they have got up but not returned in a set time. It automatically sends an alert to a carer or emergency service.

Moving and turning

If the person you are caring for needs help moving or turning, the district nurse, physiotherapist or OT can show you how to do this safely. They may be able to arrange help from care workers, or provide equipment to help you. This could include a hoist or sling.

When a person is not able to move around much, they have a higher risk of getting pressure sores. 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 ankle or elbow pads to reduce the risk of pressure sores. Gently massaging the persons 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 (see page 118). You could also speak to the GP or district nurse.

Help with medicines

You may need to help the person you are caring for take their medicines at the right times. Make sure they take them exactly as the cancer doctor or specialist nurse prescribed.

Check:

- that the person's name and medicine are correct on the label
- that the medicine is in date
- how often the medicine should be taken
- how to take the medicine, for example, with or after food.

Ask your local or hospital pharmacist for advice and information about medicines.

You may find it helpful to use a pill organiser (dosette box) or a calendar blister pack. They 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 about getting a one of these.

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 two pages to keep a record of your medications. It was developed with help from Boots Macmillan Information Pharmacists. They are available in some Boots stores and can help you with questions about medicines.

TIME**Medication:****How much to take (dosage):****What it is for:****Shape and colour:****Instructions:****TIME****Medication:****How much to take (dosage):****What it is for:****Shape and colour:****Instructions:****TIME****Medication:****How much to take (dosage):****What it is for:****Shape and colour:****Instructions:****TIME****Medication:****How much to take (dosage):****What it is for:****Shape and colour:****Instructions:**

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

Managing symptoms and side effects

The person you are caring for may have different symptoms or treatment side effects. 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 gave you. For example, you may have been told to contact the hospital directly on a 24-hour number if they have a temperature or feel unwell.

We have more information about different cancer treatments and their side effects in our booklet **Side effects of cancer treatment** (see page 114). Understanding more about this can help you support the person you are caring for.

Possible symptoms or side effects

Eating problems

Eating problems and loss of appetite are common symptoms. They can also be caused by side effects, 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 dietitian. A dietitian can give you advice on foods the person you are caring for could try. They can also give you nourishing drinks or food supplements to help. You can also get these from your pharmacy or on prescription.

What you can do

- Make small meals or snacks regularly, rather than main meals.
- If they find swallowing difficult, try snacks like fruit, nuts, grated cheese or yoghurts.
- If swallowing is hard, make foods softer using sauces, or liquidise foods.
- Add extra calories by using butter, full-fat milk, cream and honey.
- Try nourishing drinks such as smoothies or milkshakes, and add extra calories using cream or ice cream.

We have more information about eating problems in our booklets **Eating problems and cancer**, **The building-up diet** and **Recipes for people affected by cancer** (see page 114).





Sore or dry mouth

This can happen as a side effect of treatment, or because of advanced cancer. Tell a doctor or nurse if the person has a sore mouth or white patches (thrush) in the mouth or throat. It is very important these symptoms are treated. There are mouthwashes, tablets, gels or pellets to help with symptoms and reduce the risk of infection.

What you can do

- Try to get them to gently clean their teeth or dentures using a soft-bristled toothbrush. Avoid using strongly-flavoured toothpaste.
- Try to get them to keep their mouth clean by rinsing it regularly with a weak mixture of warm salt water.
- Suggest they avoid acidic drinks like orange juice, and spicy or salty foods.
- Keep their lips moist by using Vaseline® or a lip balm and encouraging them to drink plenty of fluids.
- Encourage them to avoid, or cut down on, smoking and drinking alcohol.

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

Constipation

Constipation can be caused by some chemotherapy drugs, painkillers and anti-sickness drugs. Not getting enough exercise, eating enough fibre (roughage) or drinking enough fluids can also cause constipation.

Tell a doctor or nurse if constipation is a problem. They can give you advice and prescribe medicines that will help (laxatives). Tell them if it does not improve.

What you can do

- Add more fruit and high-fibre foods to their diet. For example, add apricots, prunes, or prune juice.
- Encourage them to drink plenty of fluids.
- If possible, try doing some gentle exercise together, such as short walks.

Feeling or being sick

This can be caused by cancer, or sometimes by the treatment. If the person you are caring for is feeling or being sick, contact the hospital on the 24-hour number if you were given one. You can also contact the GP or specialist nurse. They can prescribe anti-sickness drugs. There are different types of drugs they can try.

What you can do

- Give them small meals or snacks rather than big meals.
- Avoid fatty foods or foods with a strong smell.
- Try ginger to reduce sickness – this could include crystallised ginger, ginger tea or ginger biscuits.
- Encourage them to sip a fizzy drink slowly through a straw – this could be ginger beer, soda water or lemonade.
- Have frozen meals or easy to make foods available for when they feel able to eat.

Pain

Pain can usually be well controlled with painkillers. Sometimes the person you are caring for may need a combination of different drugs. They are usually taken by mouth as tablets. Some are given as a patch stuck onto the skin that you replace every few days.

If the person you are caring for is being sick or is too sleepy to take their drugs they can have painkillers and anti-sickness drugs as an injection. This can be given through a small pump that delivers drugs continuously through a fine needle under the skin. Some types of pain can be controlled with more specialised methods, such as a nerve block.

If painkillers are not working, contact the GP, district nurse or palliative care nurse. They can increase the dose or change the drug. The person you are caring for can be referred to a specialist in pain control.

What you can do

- Help them change position regularly so they are comfortable.
- Try a heat pad to help aches, or help them to have a warm bath.
- Talk to them about how they feel to make them feel less anxious, which may help the pain.
- Try music, books, TV or doing something creative to try to help distract them from the pain.
- If pain or other symptoms are difficult to control at home, a short stay in hospital or hospice may help. They can usually control symptoms quicker than if the person stayed at home.

Our booklet **Managing cancer pain** has more information about pain control and the pain caused by cancer (see page 114).

Breathlessness

Breathlessness can be upsetting for you and the person you are caring for. But there are different things that help. 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 use breathing and relaxation techniques, or listen to our **Relax and breathe** CD (see page 114).
- Help them find a sitting and standing position that makes them feel less breathless.
- Put a seat in front of an open window and give them a small handheld fan to blow cool air on their face.
- Be with them when they feel breathless, as this is a great support.

We have more information about breathlessness and how to manage it in our booklet **Managing breathlessness** (see page 114).

Sleep problems

Controlling other symptoms, such as pain, can often help with sleep problems. If the person you are caring for is sleeping a lot during the day but not at night, ask the GP to check their medicines. This is because some medicines can affect sleep. For example, taking steroids later in the day may keep them awake at night. The GP may prescribe sleeping tablets or drugs to make it easier for them to sleep.

What you can do

- Give them a warm, milky drink or herbal tea a few hours before sleeping. Do not give them drinks with caffeine in them before sleeping.
- Try music, or a relaxation or meditation CD or podcast, to help them to relax.
- Make sure the room they are sleeping in is cool with fresh air, but not too cold.
- Make sure there is not too much light in the room they are sleeping in, and remove anything noisy.
- Check the mattress and pillows are comfortable. You can ask a district nurse or OT about a pressure-relieving mattress (see pages 34 to 36).
- If possible, keep the bedroom for sleeping only. Do not have a television, laptop or tablet in the room.

We have more information about sleep problems in our booklet **Coping with fatigue** (see page 114).



OTHER CARE OPTIONS

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Respite care

You may find you need time off from caring to have a break. This helps you look after your own health and wellbeing. It can stop you from becoming too stressed or tired to cope.

Respite care can provide short or longer breaks for carers. It could be for a few hours, an evening or a week or two. There are different options available, including:

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

To get respite care, you can ask social services for an assessment of your needs. This is called a carer's assessment (see pages 21 to 23). A carer's assessment can also be done after a needs assessment of the person you are caring for.

Some charities, such as the Respite Association, can help with respite breaks for carers. This usually involves them arranging care packages for one or two weeks, so you can get some rest. For more information, visit [respiteassociation.org](https://www.respiteassociation.org)

Ask your health or social care teams about what is available in your area (see pages 10 to 19). Carers Trust or Carers UK can also give information about what is available in your area (see page 118).

Your GP, district nurse or palliative care nurse may be able to arrange longer breaks. For example, they might arrange for the person you are caring for to spend some time in a hospice.

Sitting services

You might be able to arrange for someone to sit with the person you look after. This could be for a few hours in the day, or for an evening. Sometimes sitters can stay overnight. Some sitters also help with housework or personal care, such as washing and dressing. Different charities offer sitting services, such as Carers Trust (see page 118).

Day centres

Your local hospice or hospital may run a day centre for people with cancer. The day centre may be able to look after the person you are caring for, for a short time. Lunch and transport to the centre is often provided. Some centres offer other services, such as complementary therapies. Our booklet **Cancer and complementary therapies** has more information about these (see page 114).

Short stays

There may be times when you feel you need a longer break. Recognising when you need this is important. The district nurse or palliative care nurse (see pages 16 to 17) may be able to arrange for the person you are caring for to have a short stay somewhere. This may be in a hospice, residential home or care home with nursing (nursing home).

Having a break is a decision you need to make with the person you are caring for. They may even suggest it, especially if you are very tired. Both of you might enjoy a short break. It can help you both to feel rested and able to cope better.

You may use respite care to take a complete break from your situation. Or you may continue to visit the person during this time.

Talk to the person you are caring for about how you both feel. It is important to plan how to manage the break. Before deciding, you may both want to go and see the hospice, hospital or home, and talk to the staff. You could take other family or friends as well. This can help with any worries you both might have.



Care and residential homes

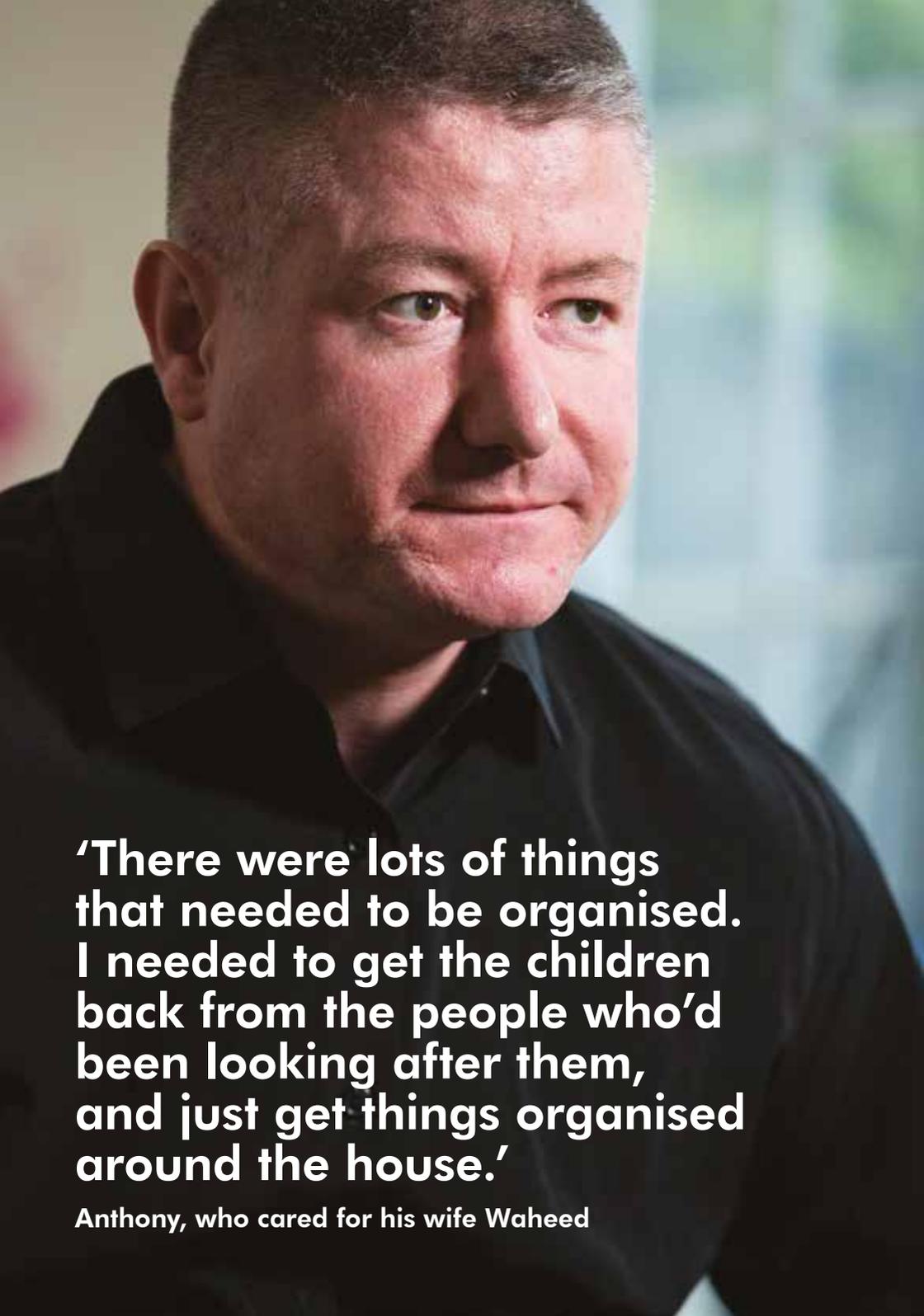
Residential care homes or care homes with nursing (nursing homes) give different levels of care. A social worker or member of the healthcare team can explain the difference. It can be short or long term. They can give you more information about:

- local care homes
- care that is given by the care homes
- things to think about when choosing a care home
- how to pay for care.

They can also help to arrange this type of care, but it may take time. Lists of local care homes are available from the adult social care department of your local authority. Care homes may not be available everywhere in the UK. Some charities offer independent advice about finding and paying for care, for example Age UK. For more information, visit [ageuk.org.uk](https://www.ageuk.org.uk)

The person you are caring for may be able to get NHS continuing healthcare. This is care for people with ongoing complex care that is paid for by the NHS. Ask a health or social care professional how you can apply for this (see pages 10 to 19).

Before choosing a care home, you may want to find out more about it. The standard of care given by care homes and care agencies across the UK is checked by the Care Quality Commission – visit [cqc.org.uk](https://www.cqc.org.uk) for more information. You can also ask your healthcare team or social worker for more information about this. They may be able to help you get a report on the care home or agency, so that you both feel confident about it.



'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, who cared for his wife Waheed

Hospice care

Care in a hospice is always free. They specialise in managing symptoms, including pain (see pages 50 to 57). They are usually smaller and quieter than hospitals. Many have sitting rooms and space for family members to stay overnight.

You might think that people are only looked after in a hospice at the very end of their lives. But hospices can also offer care to help with symptoms (palliative care), or short stays to give carers a break. Sometimes the GP, district nurse, specialist palliative care nurse or social worker may suggest that the person you are caring for goes to a hospice for a time.

Sometimes it is hard to accept that it is in the person's best interest to be cared for by health professionals. You may feel very upset and worry that they might not be able to come home again. But after a short stay, they may sometimes be well enough to come home.

The person you are caring for may have already told you that they want to be cared for in a hospice or palliative care unit at the end of their life. You may have already talked about this with them. They may have written down what they want in an advance statement. We have more information about planning ahead in our booklets **Your life and your choices: plan ahead**. There are different booklets for England and Wales, Scotland, and Northern Ireland. See page 114 for details of how to order them.

Sometimes there is a waiting list to go into a hospice, but this is usually short. If you are not sure how you feel about hospice care, you can ask to visit first. This gives you the chance to talk to staff about any worries you have.



MAKING DECISIONS AND LEGAL ISSUES

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Planning ahead

There are different ways someone can list their wishes and choices for their care towards the end of their life. It is sometimes called **advance care planning**. It is helpful for the person you are caring for to plan while they are well enough to do so, and can make decisions. Their healthcare team can tell them more about the forms they can use.

Planning ahead can help them talk to professionals and others involved in their care about what they want. As their carer, it can help you and others feel better about making these decisions, if the person becomes unable to make decisions for themselves.

Advance care planning can include:

- making an advance statement
- making an advance decision to refuse treatment (advance directive)
- creating a power of attorney
- making a will.

It may be hard to talk about these plans with the person you are caring for. We have more information in our booklet **Talking to someone who has cancer** (see page 114).

Advance statement

The person you are caring for can tell people what they want for their future care by making an advance statement. This is a written statement of their views and wishes that can be used if they become unable to make decisions for themselves. It helps carers, family, friends and healthcare professionals decide what is in the person's best interest. The person can write it themselves, or it could be a record of a conversation they have had with a GP or nurse.

It can include things like:

- what treatment they would prefer to have
- how they would like to be cared for
- where they would like to be cared for.

An advance statement is not legally binding. But anyone who is making decisions about the person's care must look at it when deciding what is best for that person. In England and Wales, a document called Preferred Priorities for Care can be used to make an advanced statement.

'Richard's disease progressed quite quickly. Knowing what might happen with an illness is important, because it enables you to plan ahead.'

Alison, who cared for her husband Richard



Advance decision to refuse treatment (ADRT) or advance directive

The person you are caring for can also decide to refuse some treatments in advance. This is called an advance decision to refuse treatment (ADRT) or advance directive. It is also sometimes called an advance decision, or living will. It is a good idea for the person you are caring for to talk about these decisions with their healthcare team (see pages 10 to 19).

Power of attorney

If the person you are caring for wants you to manage things for them, they can arrange a power of attorney. This is a legal document that gives you the authority to make decisions for them in certain situations. The person must have the ability to make their own decisions (mental capacity) when they set up the power of attorney. Depending on where they live in the UK, it can include decisions about:

- medical care and treatment
- moving into a care home
- money and property.

There are different types of power of attorney and the laws about power of attorney are different across the UK. They can be temporary or permanent. More than one person can be chosen as an attorney.

A temporary power of attorney is only for a set time. For example, it could be while the person is staying in a care home. It stops when the set time ends or the person decides to cancel it.

A permanent power of attorney

If the person you are caring for thinks they may lose the ability to make decisions for themselves, they can arrange a permanent power of attorney. This gives someone they trust the power to take over their property and financial affairs permanently. It also gives them legal permission to make decisions on the person's behalf if they become unable to do so.

This is called:

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

The person you are caring for will need to complete the power of attorney forms, and register it. It is a good idea to get advice from the local Citizens Advice (see page 122) or a solicitor.

Making a will

A will is a legal document that gives instructions about who you want to give your money and belongings to when you die.

As part of planning ahead, it is a good idea for the person you are caring for to make a will. Or they may want to update an existing will. This makes sure that their wishes will be followed when they die.

If they do not make a will, there are laws about how their property will be passed on. This includes who sorts out their estate and who their estate is passed on to. It can take much longer to sort out their estate.

A will is a legal document and must be prepared properly. But it can be simple and does not cost much. It is best to use a solicitor. We have more information about making a will in our leaflet **Your step-by-step guide to making a will** (see page 114).

Some charities offer a free will-writing service. Macmillan also offers a discounted will-writing service – visit [macmillan.org.uk/willwriting](https://www.macmillan.org.uk/willwriting) for more information.

Making difficult decisions

There may come a time when the person you are caring for 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 be resuscitated or not.

If the person has made an advance statement or advance decision to refuse treatment, you might already know their views and wishes (see pages 69 to 71). 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. Every person and their relationship with the person they are caring for is different. Use your own judgement and rely on the trust between you and the person.

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 (see pages 10 to 19). 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 not only at the end of life.



WORK AND MONEY

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Working while caring

Balancing working and caring can be hard. But if you decide to keep working, it can have some benefits. For example, working while caring can:

- give you the chance to socialise
- give you the chance to meet and share experiences with other carers in your workplace – this could be through a staff carers network
- mean you are less likely to have money worries
- giving you a separate identity from being a carer – this can be good for your confidence.

You might feel that working is an important part of who you are. Looking after yourself when you are a carer can include having your own work goals. For example, you might want to do some training or learn a new skill at work. You might need to make some changes or delay new training or learning. But you may also learn new skills as a carer that can help you in your working life.

Try to talk to your manager about your situation as soon as possible. This means they can tell you about the support available in your workplace, and the ways they can help you.

We have more information about working and caring in our booklet **Working while caring for someone with cancer** (see page 114).

Your rights at work as a carer

As a carer, there are laws that protect you from being discriminated against at work because of your connection with a disabled person. This means you have certain rights at work that may make it easier for you to keep working while you are caring.

These include the right to ask for flexible working. Flexible working arrangements could include:

- working from home
- flexible start or finish times
- compressed working hours – this means working your normal number of hours but over fewer days
- job-sharing or working part-time.

Carers who are employees also have the legal right to take a reasonable amount of time off work to deal with an emergency that involves the person you are caring for.

There is more information about your rights as a carer in our booklet **Your rights at work when you are affected by cancer** (see page 114).

'As a carer, I worry about whether I can and should have a full-time job. Flexible hours are so important to me.'

Sarifa, who cared for her husband and son

New challenges after caring

When your caring role ends, you may decide to take on a new challenge or look for a new job. You may want to bring some routine back into your life. This may be when the person you were caring for no longer needs the same help. Or it may be because sadly they have died.

Learning new skills

You may want to use certain skills again that you have not used for a while. Or you may want to learn something new. Your local library or adult education centre may be able to find suitable courses in your area. There are some useful websites you could look at for more information about courses, for example **learnirect.com** and **nationalcareersservice.direct.gov.uk**

Volunteering

Volunteering can be a great way to make a difference, meet new people and develop new skills. You might be able to help at the hospital where the person you were caring for had treatment. You could also help at your local carers' centre or volunteer for a charity. If you are interested in volunteering for Macmillan, see pages 115 to 117 or contact your local volunteering adviser.

You might be interested in becoming a Macmillan Cancer Voice. This is a UK-wide network for people to use their experiences of cancer to improve cancer care. If you are interested in being a Cancer Voice or volunteering in another way for Macmillan, contact your local volunteering adviser or search online at **volunteering.macmillan.org.uk**

Looking for a new job

You have probably learned lots of practical, organisational and communication skills from being a carer. You might find that some of the skills you have learned are valuable to employers when you apply for a new job. You could highlight this experience on your CV or on application forms.

You can get help with looking for a new job from your local Jobcentre Plus (in England, Scotland and Wales) or Social Security or Jobs and Benefits office (in Northern Ireland).



Benefits and financial support

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

You and the person you are caring for may be able to get benefits or financial support.

We have more information about financial help and benefits for carers in our booklet **Help with the cost of cancer** (see page 114). You can also call our welfare rights advisers on **0808 808 00 00** to find out more about the benefits you may be able to get.

Carer's Allowance

Carer's Allowance is a weekly benefit for people who look after someone with a lot of care needs. It is the main benefit for carers.

If there is more than one carer looking after the person, the main carer should apply. Only one person can get Carer's Allowance.

If you are receiving Universal Credit, you might be entitled to the carers element, even if you do not qualify for Carer's Allowance.

If you live in Scotland, a new extra payment is being introduced called the Carers Allowance Supplement. You can find out more about this at **gov.scot**

Carer's Credit

Carer's Credit is a national insurance credit for carers. It helps you build up qualifying years for the State Pension while you are not working.

If you get Carer's Credit you do not get any actual money, but it protects your right to a State Pension later in life.

Other benefits

You and the person you are caring for may be able to get some other benefits. These could include the following:

- Universal Credit is for people who are out of work (for example due to an illness or caring), or are on a low income.
- Employment and Support Allowance for the person you are caring for because they cannot work because of illness.
- Personal Independence Payment for the person you are caring for if they are aged 16 to State Pension age, or Attendance Allowance if they are over State Pension age. They may be able to claim if they have problems looking after themselves or moving around. People who are not expected to live longer than six months can claim under special rules and receive payments sooner.

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

You might also be able to meet a Macmillan welfare rights adviser in person through a local service. This depends on where you live. Other organisations can also help you get the financial support you need. These include your local Citizens Advice (see page 122).

Other types of financial support

There may be other types of financial support to help you and the person you are caring for. We have financial guides who you can talk to by contacting the Macmillan Support Line. They offer guidance on personal finances, including insurance, pensions and mortgages.

Grants

Macmillan Grants are small payments to help people with the extra costs that cancer can cause. They are usually a one-off payment. The person you are caring for may be able to apply depending on their income and savings. They are for people who have a low level of income and savings.

If the person you are caring for needs things like extra clothing, help paying heating bills or even a relaxing break, you may be able to get a Macmillan Grant (see page 117). Our welfare rights advisors can help you apply for a Macmillan Grant.

There may be other grants you can get. Different areas have local welfare schemes that provide grants and loans. Your local council should be able to tell you what help you can get in your area.

Help with travel costs

If the person you are caring for claims certain benefits or has a low income, they may be able to claim a refund on their travel costs for getting to and from hospital. This can include:

- bus or train fares
- some petrol costs
- taxi fares (in some situations).

Talk to the clinic staff at the hospital for more information. You could also check to see if they offer any parking discounts to people having cancer treatment and their carers.

The person you are caring for may be entitled to a Blue Badge for their car, which you can use when you are taking them out. A Blue Badge allows you to park in parking spaces closer to where you need to go.

To apply for a 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**.





EMOTIONAL EFFECTS OF CARING

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How you may feel

Caring for someone can be rewarding, but also very demanding. At times you may feel frightened, angry, guilty or lonely. The person with cancer may also have these feelings. There is information about these feelings over the next few pages.

As a carer, you may feel you should be positive for the person you look after. But no one can be positive all the time. Being positive does not mean having to feel happy and cheerful all the time. It is a positive thing to say if you are feeling tired, worried, depressed or angry, and talk about it.

Having support and people you talk to can help you cope with your feelings. People have different support networks. It could be family members, a partner, friends, health or social care professionals (see pages 10 to 19) or a support group.

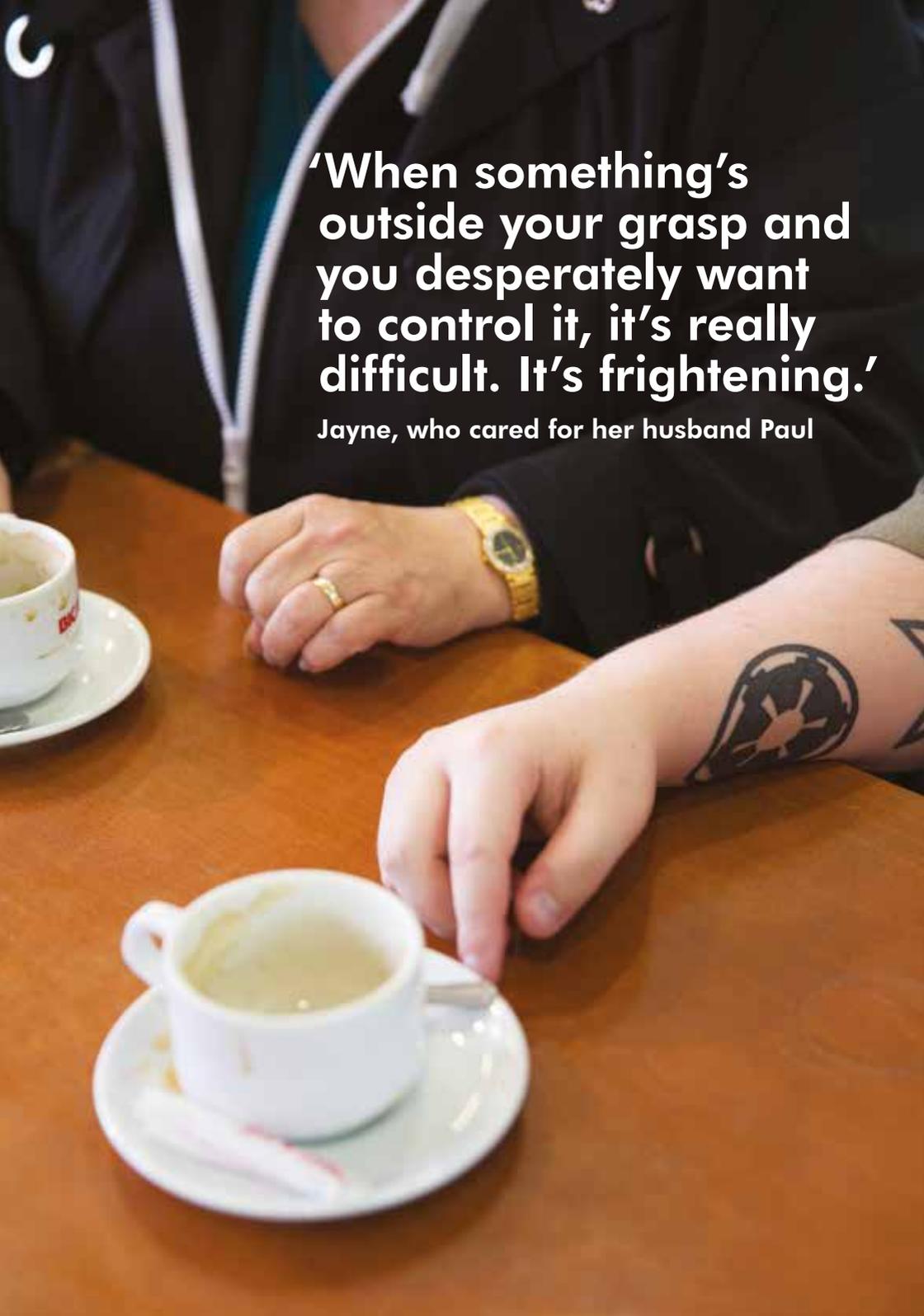
Fear

You may feel frightened or worried about the future. You may hide your feelings to avoid upsetting the person you are caring for. 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 or specialist nurse. Having more information about the cancer and what to expect may help you feel less worried and more in control.

**'When something's
outside your grasp and
you desperately want
to control it, it's really
difficult. It's frightening.'**

Jayne, who cared for her husband Paul



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.

'When I am feeling low, I know it will eventually pass and I will be able to take control again, even if I don't know for how long. Take each day at a time. I read a lot, which helps me escape from reality for a little while. Don't beat yourself up, and just do what you can when you are able to do it.'

Karen

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 are caring for may not seem to appreciate what you do for them. Or they 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. Look out for the warning signs. 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 you could act differently.
- Write about your anger – this can help release it.

'Be kind to yourself. The way you're feeling is normal – we've all felt like that from time to time.'

Caroline

Loneliness or isolation

It is not unusual to feel lonely or isolated. 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. See page 116 for more information about our Online Community.

'I knew my friends were there to support me, but I didn't feel like there was anyone I could open up to. That's when I started feeling a bit lonely'.

Ben, who cared for his mum

Guilt

You may feel guilty because you would like a break. 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.

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 are caring for. 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.

'When Waheed was going through treatment, I really focused on the practical. I didn't feel there was really much time or space to connect much with my feelings, and I put all my effort into supporting my wife.'

Anthony, who cared for his wife Waheed

Counselling

If you find it difficult to talk to people you know or 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 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 (see page 121).

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, 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 – see page 116 for more information.

Looking after yourself

It is important to look after yourself and find time to do the things you enjoy. Getting support and help from others and having regular breaks is important. This helps you to stay well and keep being a carer.

Take care of your health

- Tell your GP that you are a carer so they can give you support and advice.
- Go to any health appointments you have, for example any screening appointments.
- Check if you can get a free flu vaccination – you might be able to have one if you are the main carer.
- Tell your GP if you have problems eating or sleeping, or if you are struggling with difficult feelings or finding it hard to cope.

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.

Try to relax

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

Get enough sleep

Getting enough sleep can be difficult if you are looking after someone who is very ill. 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 (see page 118).



RELATIONSHIPS

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You and the person you are caring for

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

'I felt like the man of the house, because mum is a single parent. She ran the house herself, so when she became incapable of doing that, I had to take over. I looked after my little brother and sister. I did whatever I could to help mum and make things easier for her.'

Ben, who cared for his mum Deanne

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.

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. There is more information about this in our booklet **Talking with someone who has cancer** (see page 114).

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 the balance of your relationship. For example, you might have to take on a different role from before. 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. You may also find the information helpful in our booklet **Talking to children and teenagers when an adult has cancer** (see page 114).

We have more information about how cancer can affect your relationship with your partner in our leaflet **Cancer, you and your partner** (see page 114).

Your sex life

You may feel the intimacy you had before with your partner 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.

If you identify as LGBT+, you may worry about being treated differently by your partner's healthcare team. But telling the team about your relationship, and them recognising it, can make you both feel more supported.

We have more information in our booklet **Cancer and your sex life** (see page 114).



Your relationship with others

Being a carer can also affect your relationships with other people.

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 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, ask a health professional or social worker who is involved for advice (see pages 10 to 19).

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. You may find the information helpful in our booklet **Talking to children and teenagers when an adult has cancer** (see page 114).

'The nurse helped us figure out what might be the best way to talk to our young children about the condition, and explain it in a way they would understand.'

Anthony, who cared for his wife Waheed

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 tired.
- Your finances may be affected, which can cause worry (see pages 82 to 85). Our financial specialists can help (see page 117).

Try to talk honestly with your partner about any worries you have. If you are worried about your relationship and would like advice or information, the charity Relate can help – **visit [relate.org.uk](https://www.relate.org.uk)**. It offers counselling services in the UK for every type of relationship.

Friends

Friends may be able to give you practical and emotional support. But you may see them less often because you are a carer. 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 the support you need. 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 (see pages 10 to 19). 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 (see page 118).
- You could join a self-help and support group and speak to other carers or other people affected by cancer. For more information, visit qub.ac.uk/sites/CancerCaringCoping
- You can talk to other carers online 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. It also has information about what they have found helpful. Visit qub.ac.uk/sites/CancerCaringCoping



END OF LIFE AND BEREAVEMENT

Caring for someone at the end of life

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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, and professionals.

You may want more information about what to expect when someone dies. You could talk about this with the doctors or nurses involved (see pages 10 to 19). Palliative care nurses and doctors are used to talking about these issues.

We have more information about dying and the end of life in our booklet **End of life: a guide** (see page 114). This is a booklet for people in the final stages of life, and people caring for someone in the last few weeks of life. It might help you and the person you are caring for to plan for this time.

You may also find support and information on the Dying Matters website – visit **dyingmatters.org** It is for people nearing the end of their life. It also has information for their carers, family and friends. The Find Me Help section has information for carers on what happens at the end of life, talking to someone about dying, what to do after a death, and coping with a bereavement.

Coping with bereavement

If the person you are caring for dies, you may find our information on coping with bereavement helpful. Our booklet **After someone dies: coping with bereavement** is for the relatives and friends of anyone who has died from cancer (see page 114). Your Macmillan or hospice team may also offer a bereavement service.

You might find bereavement counselling or a bereavement support group helpful. Cruse Bereavement Care offers support and has a helpline (see page 125).

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](https://www.macmillan.org.uk/bereavementgroups)**

MACMILLAN
CANCER SUPPORT

PELVIC RADIOTHERAPY IN WOMEN



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About our information

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

Order what you need

You may want to order more booklets or leaflets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

Online information

All our information is also available online at [macmillan.org.uk/information-and-support](https://www.be.macmillan.org.uk/information-and-support) You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](https://www.be.macmillan.org.uk/otherformats)

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

Book reviews

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

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

Work support

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

Macmillan Organiser

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

Other useful organisations

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

Support for carers

Cancer Caring Coping

www.qub.ac.uk/sites/CancerCaringCoping/

CancerCaringCoping/

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

Carers Direct Helpline

Helpline and webchat

0300 123 1053

(Mon to Fri, 9am to 8pm,
Sat to Sun, 11am to 4pm)

www.nhs.uk/carersdirect

Confidential information, advice and support for carers. Offers advice on getting a break from caring, assessments, financial support, going to work.

Carers Trust

Tel (England) 0300 772 9600

Tel (Scotland) 0300 772 7701

Tel (Wales) 0300 772 9702

Email info@carers.org

www.carers.org

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

Carers UK

Helpline (England, Scotland, Wales) 0808 808 7777

(Mon and Tue, 10am to 4pm)

Helpline (Northern Ireland)

028 9043 9843

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151

www.cancerblackcare.org.uk

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

Cancer Focus Northern Ireland

Helpline 0800 783 3339

(Mon to Fri, 9am to 1pm)

Email

nurseline@cancerfocusni.org

www.cancerfocusni.org

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

Cancer Research UK

Helpline 0808 800 4040

(Mon to Fri, 9am to 5pm)

www.cancerresearchuk.org

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

Cancer Support Scotland

Tel 0800 652 4531

(Mon to Fri, 9am to 5pm)

Email info@

cancersupportscotland.org

www.cancersupportscotland.org

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

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

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

Maggie's Centres

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

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

Penny Brohn UK

Helpline 0303 3000 118

(Mon to Fri, 9.30am to 5pm)

Email

helpline@pennybrohn.org.uk

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010

(Daily, 8am to 8pm)

Email

info@tenovuscancercare.org.uk

www.tenovuscancercare.org.uk

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS.UK

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88

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

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

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

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955

Email info@ukcp.org.uk

www.psychotherapy.org.uk

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

Emotional and mental health support

Mind

Helpline 0300 123 3393

(Mon to Fri, 9am to 6pm)

Text 86463

Email info@mind.org.uk

www.mind.org.uk

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

Samaritans

Helpline 116 123

Email jo@samaritans.org

www.samaritans.org

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

Financial or legal advice and information

Benefit Enquiry Line

Northern Ireland

Helpline 0800 022 2450

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

Textphone 028 9031 1092

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

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

Carer's Allowance Unit

Tel 0800 731 0297

Textphone 0800 731 0317

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

www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

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

England

Helpline 03444 111 444

www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060

www.cas.org.uk

Wales

Helpline 03444 77 2020

www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181

www.citizensadvice.co.uk

Civil Legal Advice**Helpline** 0345 345 4345(Mon to Fri, 9am to 8pm,
Sat, 9am to 12.30pm)**Textphone** 0345 609 6677**www.gov.uk/civil-legal-advice**

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

Disability and Carers Service**Tel** 0800 587 0912

(Mon to Fri, 9am to 5pm)

Textphone 0800 012 1574**nidirect.gov.uk/contacts/disability-and-carers-service**

Manages state benefits in Northern Ireland. You can apply for benefits and find information online or through its helplines.

GOV.UK**www.gov.uk**

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

Money Advice Scotland**Tel** 0141 572 0237**Email** [info@](mailto:info@moneyadvicescotland.org.uk)moneyadvicescotland.org.uk**www.moneyadvicescotland.org.uk**

Use the website to find qualified financial advisers in Scotland.

NiDirect**www.nidirect.gov.uk**

Has information about benefits and public services in Northern Ireland.

Equipment and advice on living with a disability**British Red Cross****Tel** 0344 871 11 11**Textphone** 020 7562 2050**Email** information@redcross.org.uk**www.redcross.org.uk**

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

Disabled Living Foundation (DLF)

Helpline 0300 999 0004

(Tue to Thu, 10am to 4pm)

Email helpline@dlf.org.uk

www.dlf.org.uk

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

Disability Rights UK

Tel 0330 995 0400

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

Email [enquiries@](mailto:enquiries@disabilityrightsuk.org)

disabilityrightsuk.org

www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Support for older people

Age UK

Helpline 0800 678 1602

(Daily, 8am to 7pm)

www.ageuk.org.uk

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

LGBT+ specific support

LGBT Foundation

Tel 0345 330 3030

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

Email helpline@lgbt.foundation

www.lgbt.foundation

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

Advanced cancer and end-of-life care

Hospice UK

Tel 020 7520 8200

Email info@hospiceuk.org

www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline 0800 090 2309

(Mon to Fri, 8am to 6pm,
Sat, 11am to 5pm)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Bereavement support

Childhood

Bereavement Network

Tel 020 7843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Cruse Bereavement Care

Helpline 0808 808 1677

(Mon, 9.30am to 5pm,
Tue to Thu, 9.30am to 8pm,
Fri, 9.30am to 5pm)

Email info@cruse.org.uk

www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

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

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

Sources

We have used a number of sources in this publication. If you would like further information about the sources we use, please contact us at [**bookletfeedback@macmillan.org.uk**](mailto:bookletfeedback@macmillan.org.uk)

National Institute for Health and Care Excellence (NICE). Transition between inpatient hospital settings and community or care home settings for adults with social care needs. 2015.

NHS England. An integrated approach to identifying and assessing carer health and wellbeing. Standing Commission on Carers. 2016.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to macmillan.org.uk/donate

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

This booklet is about looking after someone who has cancer. It is for anyone who gives unpaid support to a family member, partner, friend or neighbour 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.

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

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

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

MACMILLAN
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RIGHT THERE WITH YOU

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