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 care for
• the practical, emotional and financial issues you may face, and how to cope with them
• ways you can help the person you care for manage symptoms or side effects
• how to look after yourself.

We hope this information 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.

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, Monday to Friday, 9am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.
If you are deaf or hard of hearing, call us using 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 or call 0808 808 00 00.

How to use this booklet

The booklet is split into sections to help you find what you need. You don’t 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.

We have included quotes from people who have cared for someone with cancer, which you may find helpful. These are from people who have chosen to share their story with us. Some are from Anthony and Waheed, who are also on the cover of this booklet. Anthony cared for his wife Waheed when she was diagnosed with cancer. To share your story, visit macmillan.org.uk/shareyourstory
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Caring can mean helping with everyday tasks like cooking meals.
Am I a Carer?

What is a carer?

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What is a carer?

If you give unpaid support to a family member, partner, friend, or neighbour who could not manage without this help, you may be a carer.

Not everyone sees themselves as a carer. You may think of the support you are giving as just doing your bit to help. But recognising that you are a carer can be the first step in getting the support you might need.

Caring can mean many things, including:

• giving emotional support
• helping with everyday tasks
• providing transport
• talking to others, such as health professionals, on the person’s behalf
• helping with personal care.

Every caring situation is different. You may support the person every day, or a few times each week. As well as looking after them, you may have a job or children who you look after too. You may not live with the person you care for, or be related to them.

Some people have more than one carer. The person who spends the most time looking after someone may be called their main carer.

Lots of young people are carers too. If you are aged under 18 and looking after someone with cancer, you may want to read our booklet A guide for young people looking after someone with cancer. See page 132 for information on how to order this.
‘I never thought of myself as a carer. I was just being a daughter, looking after my dad.’

Victoria, who cared for her dad
‘I only live a few blocks down the road. I come round quite a bit to cook for Patrick and tidy up.’

Ayub, who cared for his friend Patrick
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Health and social care professionals

When you are looking after someone with cancer, you may meet different members of their healthcare team.

When they are first diagnosed or having treatment, you may meet:

- a **surgeon** – a doctor who carries out operations to treat cancer
- an **oncologist** – a doctor who specialises in giving treatments for cancer, such as chemotherapy or radiotherapy
- **specialist nurses** – who give information and support.

At the hospital or at clinic appointments, you may also meet:

- **nurses** – who work in wards and clinics
- a **physiotherapist** – who gives advice on exercise and mobility
- an **occupational therapist (OT)** – who helps people who have difficulty doing everyday tasks, such as washing and dressing
- **social workers** – who assess what practical and social help you and the person with cancer needs.

The person you are caring for may have a **key worker**. This is someone who is responsible for assessing the type of help the person with cancer can get. They can also help to arrange and co-ordinate different services. The key worker may be a social worker or specialist nurse. The doctor or nurse can tell you who the key worker is.
Some people may need more practical care and support when they are at home. The person you are caring for may need help with everyday tasks, such as washing and getting dressed. If you are their main carer, you may be worried that you won’t be able to manage.

The GP is responsible for the healthcare of the person you are caring for at home. There are also community health and social care professionals who can support you. The type and amount of support you get will depend on where you live and how the services are organised in your area.

It is helpful to record the names and contact details of the professionals you meet, in case you need to contact them.

**Talking to healthcare staff**

Doctors and nurses are a good source of information to help you with caring. As a carer, you may often ask them for advice. You may also be able to give them useful information about the person’s situation at home, their symptoms and their needs. It is important to try to get the most from your conversations.

Describing symptoms or situations may be difficult, but telling staff what is happening or what help you need will help them give you the right support. Try to be open, honest and accurate. Not everyone feels comfortable being open with healthcare professionals, but it can really help. Try to use your own words and ask healthcare staff to explain unfamiliar medical terms.

Knowing what to ask during appointments or conversations can be hard. The person you care for may have questions to ask during the appointment. Check if they are happy for you to ask some questions too. You could write these down, so you don’t forget.
At the end of conversations, it can help to check you understand what you have been told by repeating back the information. If things sound quite complicated, don’t be afraid to ask for simpler explanations.

‘In the earlier meetings with doctors you’re still very much in shock with the news that you’ve received. It’s hard to be present and completely connected with everything that’s being told to you at the time. I would just jot down some of the terms and the things they’d been telling us, knowing that I’d have to re-read it to properly 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 their health or social care professionals. It describes how professionals plan to care for them and what they can do to manage their health themselves.

Ask the key worker or oncologist if a care plan has been organised for the person you care for. The plan should include information about the support they will get after treatment or after leaving hospital. Make sure you are clear about what support is available and ask to have the details explained to you.
Sharing information and confidentiality
Professionals may prefer to only share information with family members or someone named by the person you care for. If the person you care for would like professionals to share information with you, they should let them know as early as possible. You should also let their healthcare team know that you are their carer. They can then involve you in care planning and decision making.

The cancer registry

When someone is diagnosed with cancer in the UK, some information about them is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. The hospital will give information about the person, their cancer diagnosis and treatment to the registry automatically, unless they are asked not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for planning direct care or for health and social care planning and research.

Talk to a doctor or nurse if you have any questions about the registry. If someone does not want their information included in the registry, they can contact the cancer registry in their country to opt out. If you are the parent or guardian of a child with cancer, you can opt out on their behalf. There is more information at macmillan.org.uk/cancerregistry To find details about the cancer registry in your area, see page 145.
GP (family doctor)

A GP has overall responsibility for the healthcare of people who are unwell and being looked after at home. The GP can:

- assess the changing health of the person you are caring for
- give them information and support
- prescribe drugs
- organise nursing help if needed – for example, from a district nurse or specialist palliative care nurse
- refer them to a Macmillan nurse
- refer them to a physiotherapist or occupational therapist (OT)
- arrange for them to go into a hospital, hospice or nursing home, if needed – this may be to give you a break, known as respite care (see pages 66 to 68).

If the person you are caring for has moved to another area since they became ill, you will need to register them with a local GP surgery. You will need the name and address of their previous GP. Let their previous GP know what has happened.

Contact the GP if you are worried about something. This may be if you notice any new symptoms or some that are getting worse, or if there is a sudden change in the person’s condition. The GP may make a home visit, give you advice on the phone or suggest a visit to the surgery. You should also let their GP know that you are their carer. They may be able to tell you about local support services.

People with cancer in the UK can get free prescriptions. But in England, the person with cancer first needs to apply for a prescription exemption certificate. You can ask for an application form at their GP surgery or at the hospital.
GP surgeries are generally only open during the day on weekdays, but they must provide a 24-hour service. If you call for a doctor when the surgery is closed, you may be put through to an out-of-hours service.

**Out-of-hours services**

If you need to contact a healthcare professional when services are closed in the evenings or at weekends, you can usually get in touch with someone through an out-of-hours service.

Out-of-hours services generally run from 5pm to 8am on weekdays, and all day at the weekends and on bank holidays.

There are phone services across the UK that can help during out-of-hours periods:

- In England and Scotland, call the NHS on **111**. This is free to call from any phone.
- In Wales, call NHS Direct on **0845 46 47**.
- In Northern Ireland, contact numbers vary but are listed at [nidirect.gov.uk](http://nidirect.gov.uk)

During the call, a short health assessment is carried out. You may then be able to get advice from a healthcare professional, such as a nurse or pharmacist. Or they may arrange for the person you are caring for to see a GP at your local hospital.

You could also use the NHS Choices free symptom checker at [nhs.uk/symptomcheckers](http://nhs.uk/symptomcheckers)

It might be useful to ask the GP or district nurse about any signs or symptoms to look out for. Check what the out-of-hours services are in your area and save any useful phone numbers.
If the condition of the person you care for seems to be getting worse, contact the hospital, GP or key worker straight away.

**District and community nurses**

The district nurse is a key person involved in someone’s care when they are being looked after at home. They have overall responsibility for the nursing help you have and will talk to you about the care that will be provided. The district nurse may:

- assess the person’s nursing needs
- give them support and advice
- give injections
- change dressings
- give advice on nutrition, pressure area care, bowel problems and incontinence
- arrange for any special equipment to be delivered.

The district nurse can show you how to do everyday nursing tasks, if you and the person you are caring for are comfortable with this. They can show you how to wash, dress and move someone safely. You may want to ask them to do this with you the first few times, until you feel confident doing it yourself.

If the person you are caring for is getting ready to come home, the hospital or hospice staff should let the district nurse know, or the GP may arrange for them to visit. The first home visit you have will often be from a district nurse. After that, the district nurse usually organises for other nurses who work in their team to make regular visits. These are community nurses. You will usually see the same one or two nurses.
Community nurses may be able to visit up to three times a day – in the morning, afternoon and evening. This will vary depending on the needs of the person you are caring for and the services available in your area.

**Community specialist palliative care team**

Palliative care is given to help control symptoms rather than cure the cancer. Palliative care teams specialise in controlling pain and symptoms, as well as offering emotional support. The teams include specialist nurses and doctors. They are sometimes based in hospices and can visit people who are being cared for at home.

Community specialist palliative care nurses will work closely with the person’s GP, district nurse and other hospital services. The GP will tell you more about their services, how to contact them and when they are available.

**Macmillan nurses**

Macmillan nurses specialise in supporting people with cancer. They help with specialist care needs, give advice to other healthcare professionals and support people with cancer to understand their treatment options. They also have specialist training in pain and symptom control, and emotional support.

There are different types of Macmillan nurses. They usually work in the NHS and may be based in hospitals, hospices or the community.

The person you are caring for can be referred to a Macmillan nurse by their GP, their hospital doctor, a district nurse or a ward nurse.
Macmillan nurses work throughout the UK, but if there isn’t a Macmillan service in your local area, you can be referred to other specialist services.

**Marie Curie nurses**

Marie Curie nurses are trained to look after people who need palliative care. They normally provide care during the last days or weeks of someone’s life. They specialise in giving practical nursing care and can spend the night or part of the day in your home, giving you a break.

If you need extra nursing help, especially during the night, a member of the healthcare team may suggest that a Marie Curie nurse visits your home. The district nurse or community nurses will usually arrange this. The visit may be from a registered nurse or a senior healthcare assistant, depending on the needs of the person you’re caring for. Marie Curie is a charity and their services are free (see page 142).

**Occupational therapist (OT)**

Occupational therapists look at practical ways of making a home safe, comfortable and easy to live in. They help people who have difficulty moving around or doing everyday tasks such as dressing, washing and cooking.

OTs can suggest and arrange minor changes to your home (see page 37). They can also get the person a wheelchair, bath or shower equipment, or specially adapted cutlery.

Your social worker or district nurse should be able to arrange for an OT to visit your home.
Physiotherapist

If the person you are caring for has problems walking or moving around, a physiotherapist can often help. Physiotherapists give advice on exercises and ways to keep the person you are caring for as mobile as possible. They can also help with breathing exercises.

The GP, district nurse or specialist palliative care team can arrange an appointment with a physiotherapist. They can see them as an outpatient at the hospice or the local hospital. Some physiotherapists may visit people at home.

Continence adviser

The person you are looking after may be having trouble controlling their bladder or bowels. This is known as incontinence. It can be emotionally and practically difficult for both of you.

Your district nurse will be able to help with this and may suggest that a continence adviser visits you. This is a specialist nurse who can give advice and information about aids to help manage continence problems. You may also be able to get help with laundry services (see page 25).

For more information on bladder and bowel problems, visit the Bladder and Bowel Community website at bladderandbowelfoundation.org
Private nurses (agency nurses)

You can also get help from a private nurse. This can be very expensive and may only be practical as a short-term solution. But it can be useful if you are working and need a nurse at home while you are out.

There are many private nursing agencies that can supply qualified nurses to come into your home. You may want to ask the local social services or a support group (see page 113) for advice. You can still ask for advice even if the person with cancer is not eligible for care provided by social services.

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.
Social services

A social worker is responsible for assessing what practical and social help you and the person with cancer need. If you don’t already have a social worker, the GP or a nurse involved in the person’s care can make a referral. You can also contact the local social services department. You will find their number in the phone book under the name of your local authority, council or health and social care trust.

The social worker will visit and carry out a community care assessment or needs assessment. Each local authority has different ways of deciding who is entitled to support. The services available will vary from area to area.

If the person with cancer is entitled to some help, the local authority has a duty to meet their needs. The services they need may be provided by social services or other organisations, such as charities. These services include:

- home care
- meals
- laundry services for people with incontinence
- equipment and adaptations to your home (see pages 34 to 39)
- information and benefits advice (see page 91)
- respite care (see pages 66 to 68)
- sitting services.

Some services will be paid for by the NHS, so they will be free. In other cases, social services will do a financial assessment to calculate whether you have to pay something.
If the person you are caring for needs lots of ongoing care, you may be able to get **Continuing Health Care (CHC)**, provided by the NHS. Ask any health or social care professional how to apply for this.

Your social worker should stay in touch with you once the services have been put in place. They will check that the services are working and that your needs have not changed.

As well as arranging services to meet your needs, many social workers are trained in counselling and can offer emotional support.

**Carer’s assessment**

It is important to keep healthy and to balance caring with your own life, work and family commitments. You can ask the social worker for an assessment of your needs, called a carer’s assessment. This will give you the chance to talk about any help you need. You can still ask for this assessment even if the person you are caring for does not want an assessment of their needs, or has been assessed as not eligible for support.

‘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
If your carer’s assessment shows that you are eligible for support from social services, you may be able to get direct payments from your local authority. This means that you are given money to organise care services yourself, rather than the local social services organising and paying for them directly. You can ask your local council for more information about direct payments, or visit [gov.uk](http://gov.uk) or [nhs.uk](http://nhs.uk)

**Home care**

You may be able to get help around the home for you and the person you are caring for. This can give you a break and help you feel less tired.

Care attendants, also called care assistants or care workers, offer some types of support in the home. This may be to do some jobs around the house, or to sit with the person you are caring for while you have a break. They can also help with personal care, such as washing and dressing the person. Some services have care attendants who can help at night. Your local social services or the Carers Trust (see page 137) will be able to tell you what’s available in your area.

**Home helps** offer lots of services, including cleaning, washing, cooking and shopping. Home helps are only available in some parts of the UK. Your local social services, social worker, community nurse or GP will know what’s available in your area.

You can also get help around the home from a cleaning agency or by employing someone privately. But this can be expensive.

Make sure you check references of anyone who is going to be coming into the home. It can also be useful to find out what you need to do if you don’t want to continue employing someone.
Meals on wheels
It may be possible for the person you are caring for to have meals provided at home. This is often known as meals on wheels. Your local authority may provide these. Or you can get them through a private company. You will probably have to pay for this service, so it’s important to check the cost first.

You may be offered frozen meals that can be put in the freezer to keep and eat later. You may be able to borrow equipment to reheat the meals, and a small freezer if you need it. Daily hot meals are usually only provided if the person you are looking after cannot manage the frozen meals service.

A range of meals is usually available. If the person you are looking after has a special diet, this can usually be arranged. For example, they may need a kosher or vegetarian meal, or a very soft diet.

A social worker can arrange meals on wheels. If you live in England or Wales, visit gov.uk to see what services are available. If you live in Scotland or Northern Ireland, contact your local social services.

Laundry service
If you are caring for someone who is incontinent, your local social services may provide a laundry service. Or you may be able to get a grant for laundry charges. Ask the district nurse, GP or social worker about this.
Family and friends

It’s helpful to think about the kind of help you might need from your family, friends and neighbours. Building up a support network can make a big difference.

Make sure you involve the person you care for when thinking about who can help with what tasks. Some people may want to help with things like washing or shopping. Others will be happier to sit and talk to the person you are caring for so that you can have a break. Some people may be good at listening and will let you talk about your worries.

If you are feeling a bit overwhelmed, try making a list of things that you need help with. You could then ask people what they would be able to do. Some people may be able to help regularly – this could be a couple of hours a week. Others may prefer to help less often.

If you always seem to be coping with everything, your family and friends may not realise how much you need help. Or they may be waiting for you to ask for help. It’s important that you know who you can turn to and how they will be able to help. You could try identifying a few key people. They could be parents, close friends, or someone from a local support group (see page 113).

If you don’t live with the person you are caring for, and have family members and friends helping, it may be useful to keep a rota or log. This could be a record of who is helping, when they are coming and what tasks they are doing. It may help make the best use of everyone’s time and avoid confusion.
Creating a rota

We have included examples of things you could add to the rota. You could copy the table and use it for different weeks.

<table>
<thead>
<tr>
<th>Day</th>
<th>Task</th>
<th>Contact Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>8am: Saffiyah taking the kids to school</td>
<td>Saffiyah’s phone number</td>
</tr>
<tr>
<td>Tuesday</td>
<td>1pm: Pat driving to day unit for chemotherapy</td>
<td>Pat’s phone number</td>
</tr>
<tr>
<td></td>
<td>Phone number for day unit</td>
<td>Phone number for day unit</td>
</tr>
<tr>
<td>Wednesday</td>
<td>8am: Saffiyah taking the kids to school</td>
<td></td>
</tr>
<tr>
<td>Thursday</td>
<td>7pm: Stu calling physiotherapist to ask about exercises</td>
<td>Stu’s phone number</td>
</tr>
<tr>
<td></td>
<td>Physiotherapist’s phone number</td>
<td></td>
</tr>
<tr>
<td>Friday</td>
<td>5pm: Keisha cooking dinner</td>
<td>Keisha’s phone number</td>
</tr>
<tr>
<td>Saturday</td>
<td>10am: Pat doing the ironing</td>
<td></td>
</tr>
<tr>
<td>Sunday</td>
<td>4pm: Liz visiting</td>
<td>Liz’s phone number</td>
</tr>
</tbody>
</table>

Carers UK (see page 137) also has a free online and mobile app called **Jointly**, which you could also use to co-ordinate who is doing what.
Voluntary organisations and charities

Voluntary organisations and charities play an important role in providing help and support to people who are unwell, and their carers. They can also be helpful for people who don’t have family or friends that can help. They may offer:

• information
• loans and grants for aids and equipment
• holiday schemes
• financial help
• counselling
• transport
• befriending
• respite care at home
• a good neighbour scheme.

A good neighbour scheme is where local people provide practical help, usually for people who live alone. This may include shopping, picking up prescriptions and offering transport.
Some voluntary organisations also run local self-help and support groups where you can meet other carers in a similar situation. You may find you can talk with them more openly because they understand what you are going through. Local support groups often provide information and some have newsletters.

You can find support groups near you at macmillan.org.uk/supportgroups

Many voluntary organisations and charities have helplines you can call for more information and support. To find out what help is available from Macmillan in your area, call our support line for free on 0808 808 00 00. You can also contact your local Volunteer Centre. Their details should be in the phone book or online.

Carers’ Centres also provide a range of support for carers, including information, advice and training. Contact the Carers Trust to find your local Carers’ Centre (see page 137).
Amy, preparing medicine for her dad
Caring at home

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Organising help and services at home

All the practical help and services the person you are caring for needs should be set up before they go home. This is usually done by the hospital or hospice staff, with a social worker. All hospitals and organisations have policies to make sure a person is safely discharged and the care they need at home has been organised.

The person you are caring for may have a Holistic Needs Assessment before they go home. In the assessment, they will be asked lots of questions about how they are feeling and what help they need. This is to make sure that they get the right support, at the right time. Everyone involved in the person’s care should have a copy of the assessment, including their GP. You can ask the nurse about this.

We have more information in our leaflet Holistic Needs Assessment – planning your care and support (see page 132 for information on how to order this).

If there are a lot of things to talk about before discharge, the ward or hospice staff may arrange a meeting. This may involve:

- the person with cancer and you, if you are their main carer
- the doctor in charge of their care
- specialist nurses
- an occupational therapist (OT)
- a social worker.
We have more information about health and social care professionals and how they can help you (see pages 9 to 25).

If you are the main carer, you should be involved in any plans or decisions. It’s important to let the healthcare team know this. Remember that plans can be changed later if the situation changes. For example, when the person first goes home, you may not need any help looking after them. But if they start to get weaker, they may need help with personal care, such as washing, dressing and eating.

The person you are caring for should have information from the hospital or hospice to take home. This may explain the medicines and type of diet they need, and where to get more support. If the information is not clear, ask the doctor or nurse for more details.

Make sure the person you are caring for has the medicines they need when they are discharged. You will need enough to last until the GP can arrange a new prescription. You can talk to the pharmacist about this.
Practical aids and equipment

The hospital or hospice staff will talk to you both about any equipment you will need in the home. They can arrange for an occupational therapist to visit and assess the person’s home. Some hospitals and hospices can supply some equipment a day or two before discharge.

You can also hire equipment from voluntary organisations and charities, such as the British Red Cross (see page 138).

Beds and chairs

If the person you care for needs to spend a lot of time in bed, it is important that they are comfortable. The district nurse can arrange a pressure-relieving mattress, hospital bed or supportive chair.

Once the person is home, you can ask them what would help make them comfortable. They may need to try different sitting or sleeping positions. Using lots of pillows can help. V-shaped pillows can help relieve pressure on the back. If the person has swollen arms or legs, prop them up on extra pillows to help reduce the swelling.

If the person you are looking after can sit in a chair, it’s important that they are well-supported and comfortable. A physiotherapist or an OT can give you advice on this. The district nurse can usually arrange for the loan of a pressure-relieving cushion.
Commodes, bedpans and urinals

If the person you are caring for finds it difficult to get to and from the toilet, they may need a commode, bedpan or urinal. The district nurse should be able to arrange this. You can also buy these from pharmacies. Some commodes look like chairs and some have wheels.

Bathing equipment

The person you are caring for may also find having a bath or shower difficult. Using a bath chair, bath board or shower stool may help. An OT or physiotherapist will assess their needs and talk to you both about what bathing equipment would work best for your situation.

Breathing equipment

If the person you are caring for has breathing problems, their healthcare team can arrange equipment for them to use at home. This may include an oxygen cylinder or nebuliser, which gives medicines as a vapour to inhale.

Wheelchairs and walking aids

If the person has difficulty walking, a wheelchair, walking stick or walking frame can help. An OT or a member of the healthcare team should be able to arrange this.
Other equipment

There are many other smaller pieces of equipment that the person might need. These include two-handled mugs, an adjustable bed rest, bed raisers and grab rails. You can buy or hire these from shops and organisations. Or you may be able to get some equipment from your local pharmacy. Your pharmacist may also be able to tell you about local suppliers.

Some people may be able to get a Macmillan Grant (see page 100) to help pay for equipment.

The person’s health and social care teams should be able to give you advice about how to get the equipment you need.

Carers UK (see page 137) has put together a list of equipment and adaptations that you may find helpful. And there are lots of other organisations that provide equipment and advice on living with a disability (see page 138).

If you have equipment that you don’t need anymore, contact the district nurse or OT. They can help with arrangements to send it back.
Home adaptations

Before the person you are caring for goes home, they may need to arrange some changes to their home. These can make life easier and more comfortable for them.

An OT can give you advice about the safety of the house and making minor changes. For example, you may need handrails in the bathroom, or need the bed moved downstairs.

Major changes might be possible too. These could involve putting in a toilet or shower downstairs, or installing a stair lift. But these can take several months of planning and may not be possible before the person comes home. They also involve building work, which can be disturbing. You will need to discuss whether you want to make these changes.

If the person you are caring for lives in a council or housing association house or flat, changes like these are usually paid for by the local authority. But this depends on local policy and the funds available.

If they own their home or rent it privately, they may still be able to get some financial help (see page 91). Ask the OT, social worker or your local social services. You should make any claims for financial help before you start any building work.
Organising their room

It can help to get their room ready before they come home. Talk about which room they would prefer. If they cannot move around easily, they may want to be in the room nearest the bathroom.

If possible, position the bed so you can get around both sides of it. You could put a small table next to the bed, so they can keep some personal things nearby.

Ask them if there is anything they would like in the room. You could hang up their favourite pictures or photos. Or they may want a computer, TV or phone nearby.

If their room has, or is near, a gas appliance such as a gas heater, it’s a good idea to have a carbon monoxide detector fitted.

Sleeping arrangements

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

New technologies can help people living with cancer to be more independent. They can also help the people looking after them feel more supported and secure.

**Telecare** is a system that uses sensors placed around the home. These sensors can tell if there is a gas leak or fire, or if the front door has been left open. They can then send an alert to someone in a monitoring centre who can send help.

> ‘I use telecare constantly. It’s amazing. It means I can go out to work and know that he can get help.’
> 
> **Sarifa**

**Telehealth** is a similar system. It can send information from equipment, such as heart or blood pressure monitors, to someone in a monitoring centre. They can then pass it on to your GP or healthcare team. Telehealth can help with conditions such as asthma, heart failure, diabetes and high blood pressure. Carers UK (see page 137) has more information about telehealth and telecare.

There are also mobile apps designed to help carers. **My Organiser** is a free Macmillan app that can help you plan and record things like appointment times, contact details and when to take medicines. Search ‘My Organiser’ on the Apple App Store or Google Play on your phone.

**Jointly** is an app that helps you be organised and feel supported as a carer.
Managing everyday needs

Some people with cancer need more help with everyday tasks, such as bathing, dressing and cooking. They may feel weak or tired because of the symptoms or side effects of treatment (see pages 53 to 63). They may need more help because the cancer has become advanced.

There are health and social care professionals that can support you (see pages 9 to 25). Marie Curie (see page 142) also has useful videos and information to help you.

Helping someone with their everyday needs can affect your relationship with them. Some aspects of caring may make you and the person you care for feel embarrassed. We have more information to help you cope with the emotions you may both be feeling on pages 103 to 115.

‘My role as a carer was sometimes to help Katy walk, dress and get into the wheelchair. You end up doing all the driving and the household chores as well. So you have a full-time job. And then it gets into the nursing side, the bandages, sorting out the catheter and so on. So you end up in many, many roles as a carer, all of which you have to try to do as best you can. It’s a huge learning curve.’

Ciarán, who cared for his wife Katy
Washing and bathing

The person you are looking after may need help with a bath, shower or wash. Regular washing can help someone feel more comfortable and lift their mood. It may also help prevent infections. Some people with cancer spend large amounts of time in bed, which can make them feel sticky and hot. Or they may have a type of cancer or treatment that causes heavy sweating.

The district nurse or social worker may be able to arrange for a care worker to come in each day to help with bathing. If you prefer to do it yourself, the care worker can show you what to do.

Change the bed sheets as often as you can. Ask the district nurse or care worker to show you how to do this if the person cannot get out of bed.

Clothing

It’s a good idea for the person you are caring for to wear loose, comfortable clothes that are easy to get on and off. For example:

• skirts or trousers with elastic waistbands

• shoes and slippers with Velcro® straps.

Clothes that are easy to wash and dry, and don’t need a lot of ironing, are also a good choice. Or the person you are caring for may want to stay in their night clothes if they are more comfortable.

Wearing practical clothes can be helpful, but some people may prefer to wear the clothes they have always worn. This may help them to feel like themselves and feel in control.
Someone with cancer may feel colder or warmer than usual. They may be having hot flushes because of their treatment. Wearing layers that can be easily taken off and put on again can help.

**Hair care**

The person you are looking after may feel better if their hair is washed regularly. If they cannot get to the sink, you could buy a plastic hair-washing tray from a disability aids supplier (see page 138). You could try using a rinse-free, waterless shampoo (or cap) that you put directly on their hair and remove by drying with a towel. Ask at your local pharmacy for information about these products or search online.

Some hairdressers and barbers have a mobile service and will visit the person you are caring for at home, so they can get a haircut.

They may also need help with shaving. If you are unsure about this, you could ask the care worker or district nurse for advice.

If the person’s hair has fallen out because of treatment, it is important to take care of the skin on their head and other places where there was hair. Their scalp may become dry and itchy, and may be more sensitive. It can help to gently rub unperfumed moisturising cream into their scalp. It is important to check with the hospital, GP or district nurse before you apply anything to the skin.

Our booklet *Coping with hair loss* has helpful tips on coping with a dry scalp. See page 132 for information on how to order this.
Nail care

It may be possible for someone from a voluntary group to give the person you care for a manicure or pedicure at home.

Chiropodists or podiatrists will also often make home visits. This service is not always free so check first. If the person you care for is diabetic, always ask a chiropodist to cut their toenails. You can be referred to a chiropodist by your GP.

Toilet needs

If the person you are looking after is very weak, you may need to help them go to the toilet or use a commode, bedpan or urinal. This can be one of the most difficult parts of caring and you may both be embarrassed at first. The district nurse can give you some advice and, if necessary, arrange for someone to help with their toilet needs once or twice a day.

The person you are caring for may have lost some or all control of their bladder or bowel. This is called incontinence and can be very distressing for them. It can help to get some support and advice from the community nurse. The nurse or GP may also be able to refer the person you care for to a continence adviser (see page 20).

If possible, make sure their bedroom is near a toilet. You can ask the district nurse for a commode, bedpan or urinal to keep nearby.

The nurse can give you information about using incontinence sheets, pads and pants, and protective bed covers. These may help keep the bed clean and make the person more comfortable.
If these don’t help, the nurse may suggest a urinary catheter. This means a tube is put into the bladder so urine can be drained into a bag. For men, it is possible to use a tube connected to a sheath that fits over the penis. Bags and tubes can easily be hidden by bedclothes and blankets.

**Standing and walking**

You may need to help the person you are caring for with standing and walking. You can ask a physiotherapist or district nurse for advice on how to do this. It is important to make sure this is done safely, to prevent you injuring yourself or the person you are caring for. It will help if you are both wearing comfortable shoes that fit well and have a good grip on the floor. Make sure the floor is cleared of any possible trip hazards, such as shoes or bags.

**Managing falls**

The person you care for may be at risk of falling. This may be because they have problems moving around or they have had falls in the past. Their GP or district nurse can refer them to a falls prevention service. This service can vary depending on where the person you care for lives. But they may be able to get physiotherapy to help avoid falls and advice on getting rid of trip hazards.

If the person you are caring for does have an unexpected fall, don’t try to move them. You may risk injuring them more and hurting yourself. You should call an ambulance. The paramedics will check them for any injuries and will help move them back to a chair or bed.
Moving and turning

The person you are looking after may need help getting in and out of bed. The district nurse, physiotherapist or occupational therapist (OT) can show you the best way to do this. Doing this safely can help reduce risks to the person you are caring for and prevent you from injuring your back. It can also reduce the risk of falling. You may be able to use a hoist or sling, or a second person could help you. If you need more help, the district nurse may be able to arrange help from care workers.

People who are bed-bound, especially those who are very ill or very thin, are at risk of getting pressure sores. These are very uncomfortable and can become infected. To avoid getting sores, they will need to change their position regularly. If they cannot turn themselves, ask the district nurse to show you the best way of turning them.

A pressure-relieving mattress, and ankle or elbow pads will help reduce the risk of pressure sores.

If you have time and the person you are caring for wants you to, you can gently massage their back, arms or legs. People who are in bed for a long time may find this soothing. Use a light moisturising cream, such as aqueous cream, or almond or vegetable oil. This also stops their skin from drying out.

You should not massage areas that are swollen, sore, inflamed or have broken skin, including areas of lymphoedema (swelling of the arms and legs). If you are unsure, always ask the nurse or doctor before doing anything. If the person has had radiotherapy treatment, check with the hospital, GP or district nurse before you put anything on the treated area.
Your local Carers Trust (see page 137) Carers’ Centre may offer training in areas such as first aid, and moving and handling. You could also speak to your GP or district nurse. The British Red Cross (see page 138) also offers free courses on handling and can supply equipment.

**Help with medicines**

The person you are caring for may be taking medicines. These may be tablets, liquids, creams or inhalers. They may need help managing this. You could help them remember all the medicines they need to take and how often they need to take them. Or you may need to help them swallow tablets or apply creams.

It is important to check the information on the prescription label. Look for:

- the person’s name and the medicine name – is it the correct medicine?
- the expiry date – is it still in date?
- how often it should be taken
- how it should be taken – for example, is it swallowed whole or dissolved in water?

It is also helpful to check the leaflet that comes with the medicines. This will give you any special instructions, such as whether the medicine needs to be taken before or after food.
Using a medication planner
If the person you are caring for has lots of medicines to take every day, it can be difficult to keep track. A medication planner is a good way to keep a note of what needs to be taken and when. You or the person you are caring for can fill in the blank spaces with the names of medicines and details of how and when to take them.

This medication planner was developed with help from Boots Macmillan Information Pharmacists. These specially trained pharmacists are available in some Boots stores and can help you with questions about medicines. Other local pharmacists can also give you support and guidance about medicines too.

To find your nearest Boots Macmillan Information Pharmacist, visit boots.com/macmillan

You can find out more information and download more medication planners from macmillan.org.uk/carers
<table>
<thead>
<tr>
<th>TIME</th>
<th>Medication:</th>
<th>Dosage:</th>
<th>What’s it for?</th>
<th>Shape/colour:</th>
<th>Instructions:</th>
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This table is blank and ready to be filled with information about medications and dosages. Each row corresponds to a different time of day, allowing for the tracking of medication schedules throughout the week.
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<td>Lanzoprazole</td>
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<td>Stomach</td>
<td>White capsule</td>
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You could also ask the GP or pharmacist about a dosette box. This is a plastic box that has separate compartments for tablets. Each compartment can show what day and time the tablets need to be taken. The pharmacist will put the tablets into the right compartments for you, so you can take it home already made up.
Noel, making food for his partner Alan
MANAGING SYMPTOMS AND SIDE EFFECTS

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Eating problems

Some people with symptoms or side effects of treatment can have difficulty eating. Problems like a sore mouth, diarrhoea, constipation, tiredness or feeling sick can affect how well they eat. They may also find chewing or swallowing difficult. Cancer can also change the way the body uses food, so they may lose weight even if they are eating normally.

If the person you are looking after is having trouble eating, it may help to ask the health and social care professionals in charge of their care for advice (see pages 9 to 25). You can ask the GP or district nurse, or ask to speak to a dietitian. Dietitians give specialist advice to people who have eating problems or who struggle to maintain a healthy weight. They may give you a supply of supplements or nutritional drinks.

We have more information about this in our booklet Eating problems and cancer. See page 132 for information on how to order it.

We also have more information about all the following symptoms and side effects at macmillan.org.uk/sideeffects
Sore or dry mouth

A sore or dry mouth is a common side effect of cancer treatment or advanced cancer. Mouth ulcers and thrush are common. Tell the GP, specialist palliative care team or district nurse if the mouth of the person you are caring for becomes very sore or has white patches. It is very important these symptoms are treated. There are mouthwashes, tablets, gels or pellets that can help relieve the symptoms.

There are things you can do to help:

• Encourage them to gently clean their teeth or dentures using a soft-bristled or children’s toothbrush.

• Suggest they avoid things that are likely to cause discomfort, such as strongly flavoured toothpaste, acidic drinks like orange juice, and spicy or salty foods.

• Try cooking moist food, as it is often easier to eat.

• If they cannot manage solid food, try giving them soft foods such as porridge, bananas, custard, soup, yoghurt or rice pudding. You could try liquidised food, or a nourishing drink such as a smoothie.

• Keep their lips moist by using Vaseline® or a lip balm.

• Encourage them to drink plenty of fluids, and to avoid alcohol and smoking.

• If they need dental treatment, ask the dentist if they can do a home visit. They may charge for this.
Constipation

Constipation can be caused by cancer treatments and medicines, such as painkillers and anti-sickness drugs. Not eating enough fibre (roughage) or not drinking enough fluids can also make someone constipated. If the person you are caring for cannot move around much and is less active than usual, they are also more likely to become constipated.

Everyone’s bowel habits are different. But you should tell the GP, district nurse or palliative care nurse if the person you are caring for has a change in their usual bowel habit. They can give you advice about things that can help, such as changes to their diet. They may also prescribe medicines, such as laxatives. A laxative is a medicine that helps people to open their bowel.

There are things you can do to help:

- If they are managing to eat, add more fruit and high-fibre foods to their diet, such as apricots, prunes, or prune juice.
- Encourage them to drink plenty of fluids.
- If they can move around a little, suggest doing some gentle exercise together, such as walking.
Feeling or being sick

Some people with cancer feel sick (nausea) or are sick (vomit). This may be due to the cancer or its treatment.

If the person you are caring for is feeling or being sick, their hospital doctor or GP can prescribe anti-sickness drugs. If symptoms don’t improve, talk to the GP, district nurse or specialist nurse. There are different types of anti-sickness drugs they can try.

There are things you can do to help:

• Try making them small meals and snacks regularly, rather than big meals.

• Keep tinned foods and frozen meals ready for when they feel able to eat.

• Get drinks that can help with sickness, such as ginger beer.

• Avoid cooking fatty and fried foods – the smell can often make them feel more sick.
Pain

People with cancer are often worried that they are going to be in pain. Not everyone with cancer will have pain, even if the cancer is advanced. If the person you are caring for is in pain, it can usually be well-controlled with painkillers. Sometimes, the pain may be more difficult to control. So a combination of different medicines or other treatments may be needed.

The hospital doctor or GP can prescribe painkillers. They are usually taken by mouth as tablets. Some types of painkiller can be given as a patch stuck onto the skin (like a nicotine or hormone replacement patch).

If the person you are caring for is very drowsy or is being sick, they can have painkillers as an injection. Many painkillers can be given by injection, either into a muscle or often just under the skin.

If painkillers don’t seem to be working, contact the person’s GP, district nurse or specialist palliative care nurse. The dose or medicine may need to be changed.

Some painkillers can make people feel drowsy or light-headed at first, but this usually wears off after a day or so. If it doesn’t, tell their GP, district nurse or specialist palliative care nurse. They may be able to change to a painkiller that suits them better.
You may be able to help with their pain and discomfort by:

- changing their position regularly
- giving them a heat pad, a hot water bottle, or wheat bags that you can warm in a microwave
- giving them ice packs
- massaging the area that is painful
- distracting them with TV, books or music.

Sometimes just listening to their fears and worries can help them cope better with pain.

If pain or other symptoms are very severe and distressing, a short stay in a hospice may help (see page 71). The doctors and nurses there will be able to assess the pain and symptoms. They can change the dose of medicines or give new ones. This may help to control symptoms more quickly than if they were at home. Once their symptoms are controlled, they will be able to go home again.

Some types of pain can be controlled with more specialised ways, such as a nerve block. If the hospice doctor thinks this will help, the person you are caring for can be referred to a specialist in pain control.
Our Relax and breathe CD describes things that can help with breathlessness.
Breathlessness

The person you are looking after may sometimes be breathless. They may feel short of breath or their chest may feel tight. This can be scary for both of you. If they are breathless, there are treatments that may help. These may include medicines, oxygen treatment and complementary therapies. Treatments may help to:

- reduce anxiety and panic
- reduce inflammation in the lungs
- widen air passages and increase airflow
- loosen sticky spit (phlegm)
- reduce fluid in the lungs.

Medicines can be given in different ways, such as tablets, injections and inhalers. Let the doctor or nurse know if the person you are caring for has trouble swallowing, so they can find the best way to give the medicines. Some people may be referred to a special breathlessness service for advice and support.
Breathlessness can be difficult to live with, but there are things you can do to help:

- Help them to use breathing and relaxation techniques. They might find it helpful to listen to our **Relax and breathe CD** – it explains breathing techniques and describes positions that can help.
- You could help them record how breathless they get. They could use a Borg scale to note how breathless they are on a scale of 1 to 10. This may help you both know what makes it worse. You can then plan activities to avoid breathlessness as much as possible.
- Help them find their most comfortable seating and standing positions, where they don’t feel as breathless.
- Speak to their GP about any medicines that may help them.
- Have a small handheld fan ready to blow cool air towards their nose and mouth. Sitting in front of an open window may also help.

Our booklet **Managing breathlessness** has more information to help you. It also contains a Borg scale you can use to record how breathless you are. See page 132 to find out how to order it.
Sleep problems

The person you are caring for may have problems sleeping at night. If they are in pain, it can be very difficult to sleep well and their pain control may need to be adjusted.

If they are drowsy during the day and cannot sleep at night, ask the GP to check their medicines. They may be able to adjust it or prescribe sleeping tablets.

They may be anxious and find it difficult to relax. Reading, listening to music, meditating, or having a warm, milky drink or herbal tea in the evening may help. They should avoid anything with caffeine in, such as coffee, tea and cola. You can usually get relaxation or mediation CDs from your local library or you may be able to download a free podcast.

Make sure their mattress and pillows are comfortable, especially if they are spending a lot of time in bed. Ask the district nurse or OT if they need a pressure-relieving mattress (see page 34). You may be able to get a Macmillan Grant to help you buy a new mattress and some pillows (see page 100).

There are things you can do to help:

• Make sure their room is at the right temperature – it should be cool with fresh air, but not too cold.

• Make sure there isn’t too much light – you could think about getting darker curtains or putting up a blind behind the curtains. Light from phones and clocks can also disturb sleep.

• Think about removing any noise distractions, such as a ticking clock.
‘Respite care was essential really. I thought it would be a nice break for Mum but as it turned out, it was a very good break for me. I wish I’d organised that sooner.’

Fiona, who cared for her mum
OTHER CARE OPTIONS

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Respite care

When you are looking after someone with cancer, you might need to take time off caring to give yourself a break. If you don’t, you could become stressed, unwell or very tired.

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 respite care options available, including sitting services, day centres or short stays in a hospice, hospital, or care home.

To get respite care, a social worker will need to assess your needs and the needs of the person you care for. This is called a community care assessment or needs assessment (see page 22). They will then be able to tell you about the services that are available. Local authorities charge for some care services and they will give you information about how the care will be paid for.

Some charities, such as The Respite Association, can also help with respite breaks for carers. This usually involves them arranging care packages for one or two weeks so that carers can get some rest. Visit respiteassociation.org for more information.

Talking about your situation with someone else can be helpful. Ask your GP or specialist palliative care nurse about this. They may suggest some of the following care services.
Sitting services

Sometimes it is possible to arrange for someone to sit with the person you look after for a few hours in the day, or for an evening. Occasionally, sitters can stay overnight. Some sitters will also help with housework or personal care, such as washing and dressing.

Lots of charities offer sitting services, for example Carers Trust (see page 137).

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. The centre may provide lunch and some centres offer other services, such as complementary therapies. Transport to the centre is often provided.
Short stays

There may be times when you feel you need a longer break. Recognising when you need this can be very important. If you need a break, the community nurse or specialist palliative care nurse may be able to help. They can arrange for the person you are caring for to have a short stay somewhere. This may be in a hospice, hospital, residential home or care home with nursing.

Whether to have a break is a decision you need to make with the person you are caring for. They may even be the one to suggest it if you are getting very tired. Both of you might enjoy a short break, and afterwards feel rested and better able to manage again.

Some carers use respite care as a chance to get a complete break. Others may want to visit the person while they are in respite care. Talk to the person you are caring for about how you both feel about this, and how you plan to manage it. Before making a decision, you might find it reassuring to go and see the hospice, hospital or home, and talk to the staff. You could take the person you care for with you, or other family or friends.

To find out what is available in the area, ask your health or social care teams. You can also contact Carers Trust or Carers UK for more information about services in your area. See page 137 for information on how to contact these organisations.
Care and residential services

Residential care homes or care homes with nursing (nursing homes) can give different levels of care. This may be short-term or long-term. A social worker or member of the healthcare team can explain the difference. 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 the care.

They can also help to arrange this type of care, but it may take some time. Lists of local care homes are available from your local adult social care department. Care homes may not be available in all parts of the UK. There are also some charities who offer independent advice about finding and paying for care, for example Age UK. Visit ageuk.org.uk/home-and-care/care-homes for more information.

The person you are caring for may be eligible for NHS continuing healthcare. Continuing healthcare offers free care (funded by the NHS) for people who need a lot of ongoing, complex care. Ask a health or social care professional how you can apply for this (see pages 9 to 25).

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 is checked across the UK by the Care Quality Commission (cqc.org.uk). You can also ask your healthcare or social worker to give you this information. They may be able to help you get a report on the care home or agency so that you both feel confident about it.
Hospices

If the person you are caring for becomes more unwell as their illness develops, they may want to be looked after in a hospice or in a palliative care unit of the local hospital. You may have already discussed this with them and they may have written down their wishes. This is known as **advance care planning**.

People are often looked after in hospices at the very end of their life. But the GP, district nurse, specialist palliative care nurse or social worker may suggest a short stay in a hospice or hospital for other reasons. This may be because the person has symptoms that would be easier to control if they had specialist care. It may also be to give you a rest.

It can be difficult to accept that moving the person into care is the best thing to do, especially if you have been caring for them at home. You may both feel very upset that they might not be able to come home again. However, it is common for someone to go into a hospice for a short time to have their symptoms assessed and managed, and then go back home.

Care in a hospice is always free. They specialise in managing symptoms including pain. They are generally smaller and quieter than hospitals and work at a much gentler pace. Many have sitting rooms and space for family to stay overnight.

Sometimes there is a waiting list to go into a hospice, but this is usually short. If you are not sure about the idea of hospice care, you can ask to visit before making a decision. This gives you the chance to talk to staff about your worries.
‘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
Making decisions and legal issues

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Planning ahead

There are different ways that someone can record their wishes and choices for their care towards the end of their life. This is sometimes called advance care planning.

Advance care planning can help the person you are caring for think about the future. It can be a way of communicating what they want to professionals and others involved. As their carer, it may help you to feel less uncertain about making decisions. It can also make things easier for you and others close to them if they become unable to make decisions for themselves.

Advance care planning can include:

• Power of Attorney
• Advance Statement
• Advance Decisions to Refuse Treatment
• making a will.

It may feel very emotional to discuss these arrangements with the person you are caring for. We have more information about coping with difficult feelings and talking about how you feel on pages 104 to 115.
Power of Attorney

If the person you are caring for wants you to make decisions on their behalf, they can make a Power of Attorney. This is a legal document. It could give you (or someone else close to the person) the right to make decisions on their behalf, in certain circumstances. This can include decisions about their care and finances. There are different types of Power of Attorney. They can be temporary or permanent.

A temporary Power of Attorney
This is where someone is given the power to manage another person’s property and finances for a set period of time. This could be while the person you look after is staying in a care home or away on a long holiday. This is called an Ordinary Power of Attorney.

This can either be:
• a general power, where the attorney has power over all property and finances
• a specific power to deal with just one aspect, such as managing a bank account or selling a property.

An Ordinary Power of Attorney does not need to be officially registered. But it does have to be written in a certain way. This means the person you care for will need help from a solicitor. This type of power stops when the set period ends, or earlier if the person you care for cancels it.

An Ordinary Power of Attorney also comes to an end if the person who set it up loses the capacity to make decisions for themselves (their mental capacity – see page 81). They may want to consider a permanent Power of Attorney instead.
A permanent Power of Attorney
This is where someone gives another person the right to make decisions for them permanently.

This may be called a:
• Lasting Power of Attorney in England and Wales
• Long-term Power of Attorney in Scotland
• Enduring Power of Attorney in Northern Ireland.

In England, Scotland and Wales, it can include decisions about finances and property, and health and care.

In Northern Ireland, it’s not yet possible for someone to appoint other people to make decisions about their care and treatment. They can say how they would like to be cared for by using documents like the Advance Decision to Refuse Treatment.

This kind of Power of Attorney for health decisions may only come into effect once the person loses mental capacity.

Once this Power of Attorney has been made, it needs to be registered. This can take some time, so it is best to start the process as soon as possible. It’s best to get help from a solicitor.
**Advance Statement**

The person you are caring for can make an Advance Statement. This is a general statement of their views and wishes, in case they become unable to tell their healthcare team. It can include things like what treatment they would prefer and how and where they would like to be cared for. In England and Wales, people can use a document called Preferred Priorities for Care to give their Advance Statement.

An Advance Statement is not legally binding, but the healthcare team should consider it when deciding what is best for the person you care for.

There may be times when their wishes cannot be met, such as their choice to die at home. There may be a good reason for this. If they need to be in hospital, the professionals caring for them should explain why. There may also be times when you cannot cope and it has become too difficult to care for the person at home.

**Advance Decision to Refuse Treatment**

The person you are caring for can refuse specific treatments in advance. They can do this by making an Advance Decision to Refuse Treatment. This is also known as an Advance Directive or a ‘living will’. It is a good idea for them talk about these decisions with their healthcare team.
Making a will

As part of planning ahead, the person you care for should make a will. Or if they already have a will, they may want to update it. Having a will guarantees their wishes will be followed when they die. This includes their wishes about who they would like to inherit their estate (money, property and possessions).

If the person you care for dies without making a will, their estate will be passed on according to the law. It often takes much longer to deal with the estate. This may not be the way the person you care for would like to leave their money and possessions, so writing a will could be very important.

Making a will is not as expensive or difficult as you might think, but it is a legal document and must be prepared properly. It is usually best to use a solicitor who will be able to help with the wording. They will make sure the person’s wishes are clear and that they are carried out exactly as they would want.
Macmillan offers a discounted will-writing service. Visit macmillan.org.uk/willwriting
Making difficult decisions

There may come a time when the person you care for can no longer make decisions for themselves. As a carer, you may:

- need to make decisions on their behalf (if they have given you Power of Attorney)
- be asked about decisions that affect them.

For example, the doctor or nurse may ask you about stopping treatment or whether the person you care for should be resuscitated or not.

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

If you are able to talk about the options in advance, it can help if you ever need to make decisions on their behalf. Making notes when you have these conversations can help to remind everyone what was said. This can reduce the chances of misunderstandings later.

It can also help to have an open and honest discussion with the professionals involved. It is important that you know what the procedures involve and how they will affect the person you are caring for. It can be helpful to speak to their doctor to get expert medical information and advice.
If a hospice is involved in caring for the person, the staff may able to support you and offer advice. Hospices offer a range of services. They can often provide services in your home and don’t only help people at the end of life.

When decisions have to be made, talk to all of the family and friends involved to make sure you agree. The professionals can be a source of support as well.

If you find it difficult to start these conversations, you may find our booklet *Talking with someone who has cancer* helpful. It looks at some of the difficulties people may have when talking about cancer and suggests ways of overcoming them. See page 132 for information on how to order this.

**Mental capacity**

Laws are in place to protect people who are unable to make decisions for themselves. This means that a person can plan ahead for when they may not be able to make decisions on their own. This includes decisions about financial matters and their health and social care.

This means that there is guidance in place for carers to make decisions on behalf of the person they care for.

The laws about mental capacity are the:

- Mental Capacity Act 2005 in England and Wales
- Adults with Incapacity (Scotland) Act 2000
- Mental Capacity Act (Northern Ireland) 2016.
Mental capacity and advocacy

In some cases, local authorities can arrange for an Independent Mental Capacity Advocate to be involved in making decisions. This is a person who is trained to represent someone’s best interest when they are unable to.

An Independent Mental Capacity Advocate cannot make decisions. They are usually only involved in discussions when someone has no family or friends to represent them. But there are some other situations where they can become involved, for example if a family member lives far away or is not confident about representing the person. You can find out more from your local authority, or by asking a social worker or your GP.
Support with planning ahead and making decisions

Our booklet *Your life and your choices: plan ahead* has more detailed information about advance care planning and making decisions. You can also call our cancer support specialists to talk about any planning ahead or making decisions. See pages 132 to 136 for information about the support we can give you.

You can also contact the:

- Office of the Public Guardian in England and Wales. It has information about making decisions on behalf of people, or for people who would like to plan their future. Call **0300 456 0300** or visit [justice.gov.uk/about/opg](http://justice.gov.uk/about/opg)

- Office of the Public Guardian in Scotland. Call **01324 678 300** or visit [publicguardian-scotland.gov.uk](http://publicguardian-scotland.gov.uk)

- Office of Care and Protection in Northern Ireland. Call **028 9072 5953** or visit [nidirect.gov.uk](http://nidirect.gov.uk)
‘As a carer I worry about whether I can or should have a full-time job. Flexible hours are so important for me.’

Sarifa, who cared for her husband and son
Working while caring

Finding a balance between working and caring can be difficult. But carrying on working can also be positive:

• It may give you the chance to socialise.
• You are less likely to have money worries if you are working.
• It gives you a separate identity from being a carer. This can be good for your self-esteem and confidence.

However, not everyone can continue working in the same way as they did before becoming a carer. If your income drops because you stop working or work less, you may be able to get benefits and financial help (see pages 91 to 101).

Remember, you can ask your local authority for a carer’s assessment (see page 23 to 24). This will give you the chance to talk about any support that would help you balance work and caring, as well as other issues.

Support from your manager

You don’t have to tell your manager that you are a carer, but it can help. They may be able to offer you practical support and let you know about any relevant HR policies. Depending on the situation, they may be able to change your working pattern or let you work from home sometimes. It is in your employer’s interests to support you at work. This is because you may be more committed to your job, and likely to stay in it, if you are supported.
Your rights at work

You have 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 arrangements or to take unpaid time off work in an emergency. Carers are also protected by the law against discrimination at work because of their caring role.

Flexible working

By law, anyone in the UK who has worked for an employer for at least 26 weeks has the right to ask for flexible working. Flexible working means working a different pattern to the way you work now. You can apply for a permanent or temporary change. 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. For example, fitting in a five-day working week by working longer hours over four days.

• Annualised working hours – this is where you work the hours you are contracted for over the whole year (or each month) in a flexible way.

• Job-sharing or working part-time.

• Flexible holidays to fit in with when you can make other care arrangements.

You can also make an informal request for one of these flexible working arrangements. This means it is not requested under the law on flexible working. This option could be useful if you want to make a temporary or small change to the way you work now, and need the change to happen quickly. It may also be helpful if you want to try out a change before making it permanent.
Looking after someone with cancer

Going back to work

It is normal to feel nervous or emotional when you return to work after a break. Take your time to settle back in and don’t put too much pressure on yourself.

If you are going back to the same job, it can help if you and your manager have agreed on a return-to-work plan. They may let you return to work gradually. This is sometimes called a phased return to work. Or you may want to discuss changing the hours that you worked before. Talking to your manager about the different options can help you decide on a plan.

You can also talk to your manager about what you want other colleagues to know, and how comfortable you will be with people asking how you are. They can talk to people on your behalf before you return to work, if you think this would be helpful.

If you are a member of a trade union, they may be able to give you advice about what other people have found helpful in similar situations. You can also call us on 0808 808 00 00 for information about returning to work.

If you are self-employed

Being self-employed may allow you to be more flexible with your time. This can be useful when you are caring. But you may not have the same financial security as someone working for an employer. Remember that being self-employed does not mean you cannot access benefits and financial help. You can get advice about this from Citizens Advice (see pages 140 to 141).
New challenges after caring

At some point, you may decide to take on a new challenge or look for a new job. It may be something you want to do to bring some routine back into your life, for example if the person you care for has recovered.

Learning new skills

You may want to refresh certain skills that you have not used for a while, or 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 learndirect.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 care for received treatment or your local Carers’ Centre, or volunteer for a charity.

You might be interested in joining the Macmillan Cancer Voices. This is a UK-wide network for people to use their experiences of cancer to improve cancer care. If you are interested in becoming 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 gained many practical, organisational and communication skills from being a carer. You might find 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).

For more information about working while you are looking after someone, read our booklet Working while caring for someone with cancer. See page 132 for information on how to order this.
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 increased food or heating bills. Your income may fall if you have to give up work or reduce your hours.

You and the person you care for may be eligible for benefits. A range of benefits are available for full-time carers and people who are still working.

You can call our welfare rights advisers on 0808 808 00 00 to find out more about what benefits you may be able to get.
Carer’s Allowance

Carer’s Allowance is a weekly 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.

Who can claim

You might be able to claim if:

• you are aged 16 or over
• you care for someone for at least 35 hours a week.

The person you care for must already be getting certain benefits – usually one of the following:

• **Attendance Allowance (AA).** This is a benefit for people aged 65 and over who have problems looking after themselves.

• **Personal Independence Payment (PIP).** This is a benefit for people aged 16 to 64 who have problems moving around and looking after themselves. For you to get Carer’s Allowance, the person you care for must be getting the ‘daily living’ component of PIP. This means they need help with certain everyday activities.

• **Disability Living Allowance (DLA).** This is an older benefit that is gradually being replaced by PIP. For you to get Carer’s Allowance, the person you care for must be getting the ‘care component’ of DLA at the middle or higher rate. This generally means they need a lot of help during the day, at night or both.
It is worth knowing that:

• you do not need to be related to, or living with, the person you care for

• you can be working, but there is a weekly earnings limit of £116 a week (after certain deductions)

• you cannot claim Carer’s Allowance if you are studying for 21 hours a week or more.

If you are a carer but you do not qualify for Carer’s Allowance, you may still be able to apply for Carer’s Credit.

**Overlapping benefits**
Carer’s Allowance overlaps with certain other benefits, including:

• State Pension

• Severe Disablement Allowance

• contribution-based Employment and Support Allowance

• Incapacity Benefit

• bereavement benefits

• contribution-based Jobseeker’s Allowance.

The rule for overlapping benefits is that you cannot be paid both benefits at the same time. Instead, you are paid the one that is worth the most.

Even if this rule means you cannot be paid Carer’s Allowance, it may still be worth applying for it. This is because your entitlement may help you get other benefits. Or get an extra payment (Carer premium) added to some benefits.
How much you could get
Carer’s Allowance is £62.70 a week.

How to claim
It is useful to keep a diary of all the time you spend caring, as this can help with your application. If you qualify, you may be able to get other benefits.

To find out whether you are entitled to Carer’s Allowance and make an application:

• If you live in England, Scotland or Wales, call the Carer’s Allowance Unit on 0345 608 4321, use textphone 0345 604 5312 or visit gov.uk
• If you live in Northern Ireland, call the Disability and Carers Service on 0300 123 3356, use textphone 028 9031 1092 or visit nidirect.gov.uk You can also ask your local Social Security or Jobs and Benefits office for a form.

Exemption from the benefit cap
For some people, there are limits to how much they can get in benefits each week. This is called the benefit cap.

The benefit cap does not apply to people getting certain benefits. Since November 2016, this includes Carer’s Allowance in England, Scotland and Wales. In Northern Ireland, carers were already exempt from the benefit cap before this change.
**Carer’s Credit**

Carer’s Credit is a National Insurance credit for carers of working age. It helps you build up qualifying years for the State Pension while you are not working.

You need to pay National Insurance to qualify for a State Pension. But if you are a carer you might not be working, so you might not be paying National Insurance. Carer’s Credit means you are treated as though you paid National Insurance during the time you were caring.

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.

**Who can claim**

To get Carer’s Credit, you must look after one person for 20 or more hours a week.

Normally, each person you look after must be getting one of these disability benefits:

- the daily living component of Personal Independence Payment at either rate
- the care component of Disability Living Allowance at the middle or higher rate
- Attendance Allowance.

If the person you look after does not get one of these benefits, Carer’s Credit may still be given if you fill in the care certificate part of the application form. This will need to be signed by a health or social care professional.
Is it right for you?
You do not need to apply for Carer’s Credit if you are already getting benefits such as:
• Carer’s Allowance
• Income Support as a carer (or based on incapacity)
• Child Benefit for a child under the age of 12.
These benefits will automatically protect your right to State Pension.

You may benefit from claiming Carer’s Credit if you:
• look after someone for 20 to 35 hours a week
• help look after an ill or disabled person, but someone else claims Carer’s Allowance for looking after them
• look after several people, but do not care for any one person for 35 hours or more a week
• look after someone as well as doing paid work, but do not earn enough to pay National Insurance for the whole year
• look after someone and are self-employed
• look after someone and are a full-time student.

How to claim
• If you live in England, Scotland or Wales, call the Carer’s Allowance Unit on 0345 608 4321, use textphone 0345 604 5312 or visit gov.uk
• If you live in Northern Ireland, call the Disability and Carers Service on 0300 123 3356, use textphone 028 9031 1092 or visit nidirect.gov.uk You can also ask your local Social Security or Jobs and Benefits office for a form.
Other benefits

You and the person you care for may be able to get certain other benefits. These could include:

• Universal Credit, if either of you have a low income or are looking for work.

• Employment and Support Allowance for the person you care for, if they are unable to work because of illness.

• Personal Independence Payment for the person you care for if they are aged 16 to 64, or Attendance Allowance if they are aged 65 or above. They may be able to claim if they have problems with looking after themselves or moving around. People who are not expected to live longer than six months can make a claim under the special rules claim for these disability benefits. This means they will receive payments sooner.

If your caring role ends

If your caring role ends, it is important to let the benefits service know. This will help avoid problems later. If you have a low income once your carer’s benefits stop, you may be able to claim other benefits.

To let the benefits service know:

• If you live in England, Scotland or Wales, contact the Carer’s Allowance Unit. Visit [gov.uk/carers-allowance-report-change](https://www.gov.uk/carers-allowance-report-change) or call [0345 608 4321](tel:03456084321).

• If you live in Northern Ireland, contact the Disability and Carers Service on [0300 123 3356](tel:03001233356).
Help with travel costs

If the person you care 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).

They should speak to reception staff at the hospital for more information.

It is also worth checking at the hospital if they offer any parking discounts to people having cancer treatment and their carers.

The person you care for may be entitled to a Blue Badge for their car, which you can use when you are taking them out. The Blue Badge allows you to park in disabled parking spaces. To apply for a badge in England, Scotland or Wales, visit go.gov.uk/apply-blue-badge or contact your local council. In Northern Ireland, apply online at nidirect.gov.uk or call 0300 200 7818.

If the person you care for gets certain disability benefits, they may be able to get free or discounted road tax. The vehicle could either be registered in their name or your name as their nominated driver. If you live in England, Scotland or Wales, you can find out more by calling the Driver and Vehicle Licensing Agency (DVLA) on 0300 790 6806. If you live in Northern Ireland, call the Driver and Vehicle Agency on 0300 200 7861.
**Income tax refund**

You may be able to get a tax refund if you give up work, or if your income decreases. It is also worth checking whether you are still paying the correct amount of tax if your situation changes.

Your employer may be able to organise this. Or you can contact Her Majesty’s Revenues and Customs (HMRC) at [gov.uk/contact-hmrc](https://www.gov.uk/contact-hmrc)

**Grants**

You may be able to get some financial help from charities. Macmillan provides small, mostly one-off grants, to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing break, you may be able to get a Macmillan Grant.

For more information, visit [macmillan.org.uk/grants](https://www.macmillan.org.uk/grants)

**Insurance**

Some life insurance policies pay out when someone is diagnosed with cancer. Have a look through your policies, and those of the person you care for. You may find that you are covered for loss of income, medical treatment, credit cards, mortgage payments or other expenses.

Macmillan has financial guides who can help you understand your insurance policies.
Help with your rent or mortgage

If you are having difficulty paying your rent, you may be able to get Housing Benefit or Universal Credit. Citizens Advice can give you advice and information about renting (see pages 140 to 141).

If you are having difficulty paying your mortgage, contact your mortgage lender as soon as possible and explain what has happened. They may agree to suspend payments for a while to give you time to sort your finances out, or suggest that you pay only the interest on the loan for a while. Another solution is to extend the term of the mortgage so that you have less to pay each month.

We have more information about all of these benefits and ways to get financial support. You can order our booklet Help with the cost of cancer or call our financial guides for more guidance and support (see page 132 to 136).

You can also find more information on our website. We have a benefits calculator to help you find out what you might be entitled to and a budget planner to help you work out a weekly or monthly budget. Visit macmillan.org.uk/financialsupport
‘I knew my friends were there to support me, but I didn’t feel like there was anyone that I could open up to. That’s when I started feeling a bit lonely.’

Ben, who cared for his mum
EMOTIONAL EFFECTS OF CARING

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Your feelings

Looking after someone you care about can cause many different feelings and emotions. Some people find that coming to terms with cancer brings them closer together. Others may find it very difficult. Everyone’s experiences are different, but we have included some feelings and emotions that most carers say they have felt at some point.

People have different support networks. Whether yours is your family, your partner, a friend or a social group, try to talk to someone about how you are feeling (see pages 112 to 113).

Fear

Cancer can be very frightening. You may feel that you don’t know enough about it and that you have no control over what is happening or what is going to happen. The person you are caring for is probably afraid too. You may both be hiding what you really feel to avoid upsetting each other.

‘When something is outside your grasp and you so desperately want to control it, it’s really difficult. It’s frightening. It’s scary.’

Jayne, who cared for her husband Paul
It can help to find someone to talk to about your fears and worries. Just talking about them might be enough. Some people find it helpful to write down their worries and talk them through with the doctor or specialist nurse. This may help you talk to the person you care for about their fears.

**Depression**

You are bound to have times when you feel low, usually when you are very tired or anxious. Or when the person you are caring for is unhappy or needs a lot of help. These low times don’t usually last long and you will start to cope with your normal routine again within a few days.

> ‘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

If you find that you have been feeling low or tearful and it’s not improving, you could be depressed. Some people may often feel desperate or panicky, or as though they cannot be helped.

Try to talk to your GP if you think you are depressed. This can be difficult, but your GP should be able to help. They may refer you to a counsellor or prescribe medicines.
It can be hard to admit to people that you are feeling depressed. They may not realise how much strain you are under. Talk to someone if you can, and ask them to help. They may be able to sit with the person you are caring for while you have some time off.

If the person you care for is very unwell, they may become preoccupied and have low moods. If you think that the person you care for is depressed, talk to a health or social care professional.

**Resentment**

Most carers have times when they feel resentful. It’s natural to feel like this. You may not have much time for yourself to do things you enjoy. You may feel as though your own life has been put on hold.

The person you are caring for may sometimes have mood swings and seem withdrawn. They may have become more irritable since they became ill, especially if they are in pain. They may not always seem to appreciate what you are doing for them. Many people take their fear, anxiety or frustration out on the people around them. If this is happening, you may find it difficult to cope with.

Trying to talk about this may help – perhaps find a time when you both have a bit more energy and won’t be disturbed. Give yourselves a chance to try to understand how the other person feels. This can help prevent your feelings building into an argument. Or you may find it easier to talk about your feelings with someone outside the situation.
Anger

Many people say they feel bitter or angry if someone close to them has cancer. It may seem very unfair that illness has got in the way of any plans you both had.

You may have to cope with feelings of anger towards both the illness and the person you are caring for. You might find that you start to lose your temper with them, especially if they have become irritable or depressed.

Being angry with each other is normal and there is no reason to feel guilty about it. But it is important to find a way of dealing with it before it builds up too much.

Some people find that writing about their anger helps them release some of it. Or you might find it helpful to talk about it with a family member, a friend, or someone who has been through a similar experience. This could be someone from a local support group.

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

Caroline
Frustration

Caring for someone can be very frustrating. Being cared for can be frustrating too. Between you, you need to work out a way of getting along where you both feel that you have some control over your own lives.

As a carer, you need to make sure that you have time to yourself to do things you enjoy. The person you are caring for might like to have visitors and this can give you a break to go out or have a rest. It may also give others a chance to help and be involved.

If the person you are caring for is also frustrated, try to think of ways they can have some independence and freedom. If they are bedbound, you could make sure they have a phone, radio, TV, laptop or tablet nearby. Maybe they could help with some things around the home. Most importantly, make sure they are fully involved in decisions about their treatment and care.

Loneliness and isolation

If you are looking after someone full-time at home, you may not have much time to go out and socialise. If the person you are caring for is not feeling well and needs a lot of attention, it may feel easier to stay with them all the time.

You might start to think that you are the only one who can care for the person. But it is very important to see other people, even if it is just once or twice a week.

If you get used to not seeing other people, it can become more difficult to make contact. If you don’t accept offers of help or company, some people may think you don’t want to be contacted.
They may think you are too busy looking after the person you care for. If you find you are losing touch with friends or family, it can help to try and have regular phone calls with them.

If you feel like you don’t have anyone to talk to, you could try contacting a local or online support group (see page 113). Sharing your experiences with other people in a similar situation can really help you feel less alone.

Guilt

Most of us feel guilty about something. We all sometimes feel that we could have done more or that something we did was wrong. Sometimes these feelings can get out of control and you may forget about how much you have done to help. You may not feel good about yourself and start to believe that you can’t do anything right.

The person you are caring for may also feel guilty, perhaps about how much work and stress the illness is causing you and the rest of the family.

Try not to feel guilty for long. It can help to focus on the positive things you are doing to help the person you are looking after. Many people find sharing these feelings with someone can help them to see that feeling guilty is not helpful. You could try talking to people in a similar situation, such as other carers.
Being positive

You may feel like you should be positive for the sake of the person you look after. Some people may say you should keep being positive, to help you and the person through this difficult time. But it is natural to have times when you feel low. Being told to be positive when you feel low can be frustrating. Even if someone is just trying to help, it can feel like they are not accepting how you really feel.

People can be positive in different ways. What works for one person may not work for another. Being positive does not mean having to feel happy and cheerful all the time. If you are feeling tired, worried, depressed or angry, it can be positive to acknowledge this and talk about it with someone.

No one can be positive all the time. It is important not to feel like you must always stay on top of things.
‘When Waheed was going through treatment, I really focused on the practical. I didn’t feel there was really 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
Talking about your feelings

The feelings that you have when you are looking after someone can be hard to deal with. Trying to be open about the way you are feeling may help you to feel more in control. If you cannot talk about this with the person you are caring for, try talking to a family member, a friend or a health professional.

Your feelings may be easier to deal with once you have talked about them.

Many people find it difficult to be open in this way, especially when they are faced with a new and stressful situation. Some carers are uncomfortable talking about their own feelings with the person they are caring for because they don’t want to upset them. Others may be worried about getting upset and crying in front of them.

Some people are simply not used to talking with each other about their feelings.

There is no right or wrong way of communicating. Often just being there, perhaps giving them a hug or holding hands, is enough to show someone that you care. Be prepared for them to talk about their illness if they want to. They probably don’t expect you to have the answers, but just want you to listen and understand so they don’t feel alone.

If you both find it hard to talk about your feelings, it may be easier to talk to someone you don’t know. This could be a counsellor, someone in a support group, or a health or social care professional (see pages 9 to 25).
Counselling

If you find it difficult to talk to people you know or you don’t have anyone to talk to, it may help to talk to a trained counsellor. They will listen carefully to what you say. They have the skills and understanding to help you explore your feelings and find ways of coping with them.

Your GP may refer you to a counsellor. Your local support group or hospital information centre may be able to put you in touch with one. The British Association for Counselling and Psychotherapy (see page 139) can also give you details of counsellors in your area.

Support groups and online support

Support groups can be a good way to talk to other people in a similar situation. Some groups are specifically for people who are caring for someone with cancer. You can meet other carers who may understand what you are going through.

You can find more information about support groups from your local council or cancer hospital. You can also find a support group in your area at macmillan.org.uk/inyourarea

If you use the internet, you may want to join an online support group or chat room. This can be a helpful way of getting in touch with lots of people who may be in a similar situation to you. They are easy to join and you can stay anonymous if you prefer.

Our Online Community is a place where you can make friends, blog about your experiences and join groups to meet other people going through the same things. It has a specific group for carers at macmillan.org.uk/carersgroup
Looking after yourself

It is important to look after yourself too. Make sure you keep up with your own health appointments, including any vaccinations you need, such as the flu jab. If you are taking any medicines regularly, it is important you have a supply of these.

Take breaks

Having some time to yourself can help you relax and feel more able to cope. This can help the person you are caring for too. You may be able to arrange for some help in the home for a few hours, so you can have a break (see page 24).

When you get time off, even if it is very short, try to relax or do something you enjoy. This might be reading, going for a walk or meeting friends.

Eat well

Try to eat healthily. If you can, make time to prepare and sit down for a cooked meal. If you don’t have time, perhaps you could ask a friend to help you. And remember to treat yourself to your favourite foods sometimes too.

Be active

Try to be active and get some fresh air every day. You could go for a short walk or just go outside for a while. This will help keep you more mentally alert, and may help you feel less tired and stressed.
Try to relax

You may want to learn relaxation techniques, using CDs, DVDs or podcasts. These may be available at your local library, or you can try searching online.

Some people find having a massage very relaxing and a great way to switch off for a short time. Your local Carers Trust Carers’ Centre (see page 137) or Macmillan Information and Support Centre may offer free complementary therapies for carers.

Get enough sleep

Getting enough sleep can be difficult too. Many people say that when they are caring for someone who is very ill, they find it difficult to relax at night. You may be thinking and worrying about them and this can keep you awake.

If you live with the person you care for, you may need to help them regularly during the night. Some services have care attendants 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.

We have information for people with cancer who have difficulty sleeping at macmillan.org.uk/difficultysleeping You might find some of the tips helpful too.
‘You see things that you should never have to see and do things for the people you love that you should never have to do – but you do them, because that’s how you get through it.’

Jayne, who cared for her husband Paul
# Relationships

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You and the person you care for

Whether you care for a family member, partner, friend or neighbour, you may find that cancer affects your relationship.

Every relationship is different, but these general tips can sometimes help:

• Try to be open and honest with each other. You may both be trying to protect one another and find it hard to show your true feelings. There will be good days and bad days, but talking about how you feel could help (see pages 112 to 113).

• It is important to keep nurturing the relationship you had with one another before the cancer. Try to be understanding and supportive.

• Try to keep a routine and sense of normality.

• Try to be yourself. Behaving differently can make the person you care for feel more aware of the condition they have.

• Patience and humour can be really important – don’t be afraid to laugh.

• Let the person you care for know that although you are there to help, they are still in control. Make sure they always have a choice in decisions that affect them.

Macmillan has online courses that may improve the way you communicate with the person you care for, and your family and friends. Visit learnzone.org.uk/public to find out more.
Caring for a family member

You may be looking after a parent, grandparent, brother or sister, or child. Caring for them may mean a big change in your relationship with one another.

For example, if you are looking after a parent with cancer, you may both feel as though your roles have been reversed. You are now looking after them, rather than the other way around. You may miss the old relationship you had with them, and find it hard to see them struggle. But for some people, caring for a parent can be a chance to grow closer to them again.

‘I felt like the man of the house because my mum’s a single parent. She ran the house herself, so when mum 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 you are caring for your child who has cancer, you may find it useful to read *Children and Young People with Cancer: A Parent’s Guide*. This is available from the Children’s Cancer and Leukaemia Group at [cclg.org.uk](http://cclg.org.uk)
Caring for your partner

Looking after your partner could affect different aspects of your relationship. This could include your everyday roles and responsibilities, and your plans for the future.

If you or your partner feel that you need help with your relationship, you may find it helpful to talk to a professional, such as a counsellor. You could speak with your GP about this or talk to a local cancer support centre if you have one, such as a Macmillan Cancer Information and Support Centre. Or you might find it helpful to join a local support group (see page 113).

You could also contact the charity Relate (see page 140).

Your sex life

If you are caring for your partner, it is normal for your sex life and how you both feel about sex to be affected. However, sex may be one of the things that brings normality to your lives. Talking openly to your partner about how they feel can help.

If cancer or its treatment are causing side effects, such as pain or sickness, they may not feel like having sex. They may need time to recover. Their cancer nurse may be able to suggest things that could help with difficulties having sex.

If treatment has changed how your partner looks, it may affect how they feel about their body. This is sometimes called body image.

Our booklet Body image and cancer talks about things someone can do to adjust and build confidence if their body image changes.
Remember that doctors and nurses will have experience of talking to other carers and people with cancer about sensitive issues like sex. If you feel comfortable, talk to them about any concerns. They can give you advice on how your sex life may be affected and things that may help you.

We also have information booklets about cancer and your sex life, for women and for men. See page 132 for information on how to order these.

Caring for a friend or neighbour

If you are looking after a friend or neighbour, you may find yourself giving more support as time goes on. You may be happy to offer this help, but if it gets too much, your relationship with them may be affected.

Try to talk to them honestly about how much you feel able to help. If you are worried because you feel you are the only person who can help them, it can help to mention this to their family, doctor or social worker when you see them. As their carer, you can ask that the person has a community care assessment (also called a needs assessment – see page 22). This means that social services will assess them and decide how to meet their needs. The person who is ill or their family can also request this.
Your relationships with others

Family

When a family member or someone close to the family is seriously ill, relationships may change. If there are already issues or tensions, these can get worse in stressful situations. Spending time together and talking openly can help. It can even bring you closer together.

Be honest with your family about how you feel and make sure you give each other space when needed. Conversations may sometimes be difficult or emotional.

Some people may want to talk about what is happening and express their emotions more than others. If you are the main carer, other family members may turn to you for updates and emotional support. Some people may find that talking to you helps them feel involved in the situation. But while it is good to talk, try not to take on other people’s problems. You won’t be able to please everyone, so try not to worry about it too much. It may also be helpful to ask another family member to help give updates to the wider family.

If you are finding family relationships difficult, it may be helpful to get support from a counsellor, health professional, or someone outside the family.

You will have a lot to cope with, and it may help to write down a list of priorities. If there are children or teenagers in the family, it may be their first experience of dealing with a serious illness. You might find it helpful to read our booklet Talking to children and teenagers when an adult has cancer.
'The nurse helped us figure out what might be the best way to talk to our young children about her condition, and explain it in a way that they would understand.'

Anthony, who cared for his wife Waheed

Your partner

Your partner can be an important source of support for you if you are caring for someone else. Your caring role may also affect your relationship in other ways:

- You may have less time to spend together.
- You may find your sex life is affected, for example because you are often very tired from your caring role.
- Caring could affect your financial situation. As a couple, you may both find this a worry. See pages 91 to 101 for more information about financial support.

It is best to talk openly and honestly with your partner about any concerns you have. If you would like advice or information because you’re worried about your relationship, the charity Relate can help (see page 140).
**Friends**

Your friends, colleagues and neighbours may be able to give you practical and emotional support.

You may see your friends less often because you are busy caring. Sometimes people might not contact you because they are worried about what to say. You could try reassuring them by starting the conversation and talking openly about what has been happening. This could help them recognise that you want to talk about it, if that’s how you feel.

‘My friends drifted away, they still call me once a month or so, but I can’t go out anymore. I don’t think they realise how full-on my life is now. I do have a wonderful boyfriend who helps me cook dinner and he and his family have been there for all of us.’

Amy, who cared for her dad
If you live alone or don’t have support

Not everyone will have support from family or friends when they are caring for someone with cancer. If you don’t have this kind of support, there are services and organisations that can help. If you feel isolated, you could talk to them about any difficulties you are facing.

You could join a self-help and support group and speak to other people affected by cancer (see page 113).

You can also talk to other people affected by cancer online. Our Online Community is a social networking site where you can blog about your experiences, make friends and join support groups. There is a specific group for people who are caring for someone at macmillan.org.uk/carersgroup Here you can share your thoughts and feelings, and get support from other carers.

If you prefer talking to someone over the phone, you can call our cancer support specialists on 0808 808 00 00. They will try to answer your questions but are also there if you just want a chat.

You can also get confidential information and advice by calling Carers UK. The Carers Trust also provides support and advice across the UK. Page 137 has all the contact details you need.
END OF LIFE AND BEREAVEMENT

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Caring for someone at the end of life

While many people with cancer get better, others sadly will not. If you are caring for someone who is dying, this may be very difficult to come to terms with.

The person you are caring for may also find it hard to cope with their feelings. Talking openly with them could make it less frightening for you both and bring you closer together.

Looking after someone who is dying may be a very emotional time. You are likely to need extra help and support from family, friends, and professionals.

You may want to know what it is like to be with someone when they die. You can talk to the healthcare team about what to expect. They may be able to help with any questions you have.

We have more information to help you plan for this time in our booklet *End of life: a guide*. You and the person you care for may find it helpful. See page 132 on how to order this.

You may also find support and information from Dying Matters at [dyingmatters.org](http://dyingmatters.org) The ‘find me help’ section is aimed at people living with an illness and their carers.
Coping with bereavement

Talking about your feelings may help you cope.

If the person you are caring for dies, you may find bereavement counselling helpful. Cruse Bereavement Care may be able to offer you the support you need (see page 142).

You might also find it helpful to read our booklet *After someone dies: coping with bereavement*. It gives you practical information about what to do and expect when someone dies. It also looks at some of the emotions you may have, and the support that can help.

Macmillan has two bereavement groups on its Online Community, which many people find helpful. Visit [macmillan.org.uk/bereavementgroups](http://macmillan.org.uk/bereavementgroups)

You can also phone the Macmillan Support Line on 0808 808 00 00 for information and support.
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About our information

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

Order what you need

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

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](http://macmillan.org.uk/cancerinformation)

There you’ll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](http://macmillan.org.uk/otherformats)

If you’d like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on 0808 808 00 00.
Help us improve our information

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

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

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

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

Talk to us

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

Macmillan Support Line
Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:
• help with any medical questions you have about your cancer or treatment
• help you access benefits and give you financial guidance
• be there to listen if you need someone to talk to
• tell you about services that can help you in your area.

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

Information centres
Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you’d like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

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

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

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

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

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

Mal
Help with money worries

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

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

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

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

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

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.

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

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

Support for carers

**Carers Direct Helpline**

*Helpline* 0300 123 1053  
(Mon to Fri, 9am to 8pm,  
Sat to Sun, 11am to 4pm)  
[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)  
Confidential information and advice for carers. Offers advice on assessments, financial support, getting a break from caring, going to work and more.

**Carers Trust**

*Tel* (England) 0300 772 9600  
*Tel* (Scotland) 0300 123 2008  
*Tel* (Wales) 0292 0090 087  
*Tel* (Northern Ireland)  
028 9099 9476  
*Email* support@carers.org  
[www.carers.org](http://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 to Fri, 10am to 4pm)  
*Helpline* (Northern Ireland)  
028 9043 9843  
*Email* advice@carersuk.org  
[www.carersuk.org](http://www.carersuk.org)  
Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area. Equipment and advice on living with a disability.
Looking after someone with cancer

LGBT Foundation
Helpline 0345 330 3030
(Mon to Fri, 10am to 10pm, Sat 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation/information-advice/carers
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 and well-being, relationships, being a carer, mental health, community groups and events.

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.

Disability Rights UK
Tel 0207 250 8181
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email enquiries@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.

Disabled Living Foundation (DLF)
Helpline 0300 999 0004
(Tues to Thurs, 10am to 4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.
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

Emotional and mental health support

Inspire Mental Health (Northern Ireland)
Email mentalhealth@inspirewellbeing.org
www.inspirewellbeing.org
A network of support services throughout Northern Ireland.

Mind (England and Wales)
Helpline 0300 123 3393
or text 86463
(Mon to Fri, 9am to 6pm)
Email info@mind.org.uk
www.mind.org.uk
Provides information on all aspects of mental health, including legal matters.

Samaritans
Helpline 116 123
Email jo@samaritans.org
www.samaritans.org
Samaritans branches are located across England, Scotland, Wales and Northern Ireland. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

The Scottish Association for Mental Health (SAMH)
Tel 0141 530 1000
(Mon to Fri, 9am to 5pm)
www.samh.org.uk
Has support services across Scotland for mental health social care support, homelessness, addictions and employment services.
Relationships

Relate
Tel 0300 100 1234
(Mon to Thurs, 8am to 10pm, Fri, 8am to 6pm, Sat, 9am to 5pm)
Email relate.enquiries@relate.org.uk
www.relate.org.uk
Offers relationships advice and counselling by phone, through its website and through local services.

Relationships Scotland
Tel 0345 119 2020
(Mon to Fri, 9.30am to 4.30pm)
Email enquiries@relationships-scotland.org.uk
www.relationships-scotland.org.uk
A network of local services for individuals, couples and families experiencing relationship difficulties in Scotland.

Financial or legal advice and information

Benefit Enquiry Line
Northern Ireland
Helpline 0800 220 674
(Mon, Tues, Wed and Fri, 9am to 5pm, Thurs, 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.

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 one of these websites:

England
Helpline 03444 111 444
Email debt.advice@citizensadvice.co.uk
www.citizensadvice.org.uk

Wales
Helpline 03444 77 2020
www.citizensadvice.org.uk/wales
Scotland
www.citizensadvice.org.uk/scotland

Northern Ireland
Helpline 0800 028 1181
Email debt.advice@citizensadvice.co.uk
www.citizensadvice.co.uk/nireland

Civil Legal Advice
Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm)
Minicom 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 isn’t your first language.

Department for Work and Pensions (DWP)
Personal Independence Payment (PIP) Helpline 0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer’s Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thurs, 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.

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

NiDirect
www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.
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. Has a directory of hospice services in the UK and free booklets.

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

Childhood Bereavement Network
Tel 020 7843 6309
Email cbn@ncb.org.uk
www.childhoodbereavementnetwork.org.uk
A UK-wide federation 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 to Fri, 9.30am to 5pm)
Email helpline@cruse.org.uk
www.cruse.org.uk
Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website.
Further information

General cancer support organisations

**Cancer Black Care**
Tel 020 8961 4151  
Email info@cancerblackcare.org.uk  
[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)  
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

**Cancer Focus Northern Ireland**  
Helpline 0800 783 3339  
(Mon to Fri, 9am to 1pm)  
Email nurseline@cancerfocusni.org  
[www.cancerfocusni.org](http://www.cancerfocusni.org)  
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

**Cancer Support Scotland**  
Tel 0800 652 4531  
(Mon to Fri, 9am to 5pm)  
Email info@cancersupportscotland.org  
[www.cancersupportscotland.org](http://www.cancersupportscotland.org)  
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

**Maggie’s Centres**  
Tel 0300 123 1801  
Email enquiries@maggiescentres.org  
[www.maggiescentres.org](http://www.maggiescentres.org)  
Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

**Penny Brohn UK**  
Helpline 0303 3000 118  
(Mon to Fri, 9.30am to 5pm)  
Email helpline@pennybrohn.org.uk  
[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)  
Offers a combination of 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, an ‘Ask the nurse’ service on the website and benefits advice.

General health information

Health and Social Care in Northern Ireland
www.hscni.net
Provides information about health and social care services in Northern Ireland.

Healthtalk
Email
info@healthtalkonline.org
www.healthtalk.org
Has information about cancer, and videos and audio clips of people’s experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS Choices
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 44 888
(Daily, 8am to 10pm)
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.
Cancer registries

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

National Cancer Registration Service (England)
Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk

Scottish Cancer Registry
Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/
health-topics/cancer/
scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)
Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry
Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

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

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

Thanks

This booklet has been written, revised and edited by Macmillan’s Cancer Information Development team. It has been approved by Dr Sara Booth, Macmillan Consultant in Palliative Medicine and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Charlotte Argyle, Macmillan Carers Support Programme Manager; Lisa Dadswell, Boots Macmillan Information Pharmacist; Mary Edwards, Operations Manager – Employers for Carers, Carers UK; Marnie Enever, Macmillan East Kent Volunteer Manager, Crossroads Care Kent; Katy Herbert, Boots Macmillan Information Pharmacist; Chris Hewitt, Clinical Psychologist; Sara Lister, Head of Pastoral Care and Psychological Support, The Royal Marsden NHS Foundation Trust; Matt Loveridge, Clinical Nurse Specialist; Victoria MacLean, Macmillan Carers Support Programme Officer; Tina O’Hara, Nursing Team Leader; and Melanie Strickland, Macmillan Senior Solicitor. Thanks also to the people affected by cancer who reviewed this edition and those who shared their stories.

Sources

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

NICE guidelines. Transition between inpatient hospital settings and community or care home settings for adults with social care needs. 2015.
Can you do something to help?

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

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

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

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

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

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

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

Call us to find out more
0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other Name
Surname Address Postcode Phone Email

Please accept my gift of £
(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from Expiry date

Issue no Security number

Signature

Date / /

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.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, Monday to Friday, 9am 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.

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