

Cancer and dementia

A guide for carers



Created in partnership with

About this booklet

This booklet is about cancer and dementia. It is for anyone who looks after a friend or family member who has both cancer and dementia. We have written it in partnership with Dementia UK.

Managing cancer and dementia can be very difficult for you and the person you care for. This booklet talks about some of the worries you may have and ways to cope. It also gives practical information about getting help and support.

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

We cannot give advice about the best treatment for the person you care for. You should talk to their doctor, who knows their medical history.

We have another booklet called [A guide for people with cancer and dementia](#), which the person you care for may find helpful.

How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish.

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

At the [end of the booklet](#), there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who look after someone with cancer and dementia, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on [0808 808 00 00](tel:08088080000), 7 days a week, 8am to 8pm, or visit macmillan.org.uk

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

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

We have some information in different languages and formats, including audio, easy read, Braille, large print, interactive PDFs and translations. To order these visit macmillan.org.uk/otherformats or call [0808 808 00 00](tel:08088080000).

The language we use

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

Contents

Understanding cancer and dementia	5
Dementia and treatment for cancer	11
Planning for the future	25
Symptoms and side effects	35
Practical help and support	49
Living with cancer and dementia	61
Caring for someone with cancer and dementia	67
Work, money and benefits	77
Further information	85



Understanding cancer and dementia

About cancer and dementia

6

What is cancer?

7

About cancer and dementia

Each year, about 375,000 people in the UK are diagnosed with cancer. And it is estimated that 944,000 people in the UK are living with dementia. Many people with dementia are also living with other health conditions, including cancer. In people aged 75 or older with cancer or dementia, 1 in 13 have both conditions (around 8%).

Many people with dementia are cared for at home by a family member or friend. In the UK, about 700,000 people are unpaid carers of someone with dementia.

The main risk factor for both cancer and dementia is age. Dementia mainly affects people over 65. But it can also affect younger people. When symptoms of dementia develop before the age of 65, it is described as 'young onset'.

If you care for someone who has both cancer and dementia, it can be very difficult for you and the person you care for.

What is cancer?

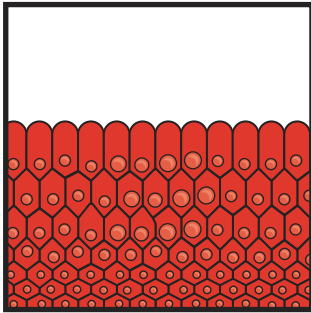
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

The instructions send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

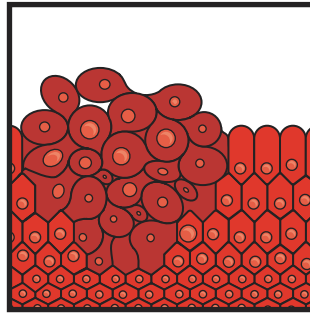
Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

8 [Cancer and dementia: a guide for carers](#)

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body.

Cancer can spread from one place (the primary site) to another through the blood or lymphatic system. When cancer spreads and grows somewhere else, it is called secondary cancer or a metastasis.

Treatments for cancer

The main treatments for cancer are:

- surgery
- radiotherapy
- chemotherapy
- hormonal therapy
- targeted therapy
- immunotherapy.

The treatment depends on:

- the type of cancer
- where in the body the cancer started
- the size of the cancer
- whether the cancer has spread to other parts of the body
- the person's general health
- any other conditions they have, such as dementia.

Cancer teams consider all these things when planning treatment. Some people may have a combination of treatments.

We have more information about all these treatments on our website. Visit [macmillan.org.uk/treatments-and-drugs](https://www.macmillan.org.uk/treatments-and-drugs)





Dementia and treatment for cancer

Treating cancer in someone with dementia	12
Planning ahead	18
Appointments and hospital visits	19

Treating cancer in someone with dementia

Having dementia usually involves problems with memory, reasoning and managing daily life. The cancer treatment offered to the person you care for will depend on the type and stage of cancer they have. But it will also depend on the dementia symptoms the person has and how they cope with possible treatments.

We have more information about the stage of cancer at [macmillan.org.uk/staging-and-grading](https://www.macmillan.org.uk/staging-and-grading)

The cancer team can talk to you both about the aims of the cancer treatment as well as the risks and benefits of different treatment options.

Aims of cancer treatment

Treatment can aim to:

- completely remove the cancer or destroy all cancer cells
- slow down, or help to control, the growth of a cancer
- relieve symptoms
- give the best quality of life.

Benefits and risks of treatment

The cancer doctor will talk to you and the person you care for about the possible risks and benefits of different treatments. This can help with any decisions you both need to make about possible treatment.

Some people will be offered the standard treatment for their type of cancer. Standard treatment means the most effective treatment that is available now. Some treatments might mean the person you care for needs to spend time in hospital.

Most people have some [side effects from cancer treatment](#). These are usually temporary and can be helped with medicines. But some people have longer-lasting side effects known as late effects. We have more information about late effects on our website. Visit [macmillan.org.uk/late-effects-of-treatment](https://www.macmillan.org.uk/late-effects-of-treatment)

For some people, treatment will cure or control the cancer. But sometimes treatment may not work as planned.

Sometimes, standard treatment may not be an option. This may be because the person is not well enough. Or they may have other health problems. Instead, they may have other treatments with:

- lower doses of medicine
- fewer treatment sessions.

Making decisions

Having dementia may mean that the person you care for is less able to understand and remember information about:

- their cancer diagnosis
- treatment options.

But it is important that people with dementia and cancer feel supported in making their own decisions for as long as possible.

It can help to think about how cancer treatment may affect you and the person you care for. For example, some treatments may make the person very tired or more forgetful. Other treatments, such as radiotherapy, may mean daily hospital visits for several weeks. Or the person you care for may have to lie very still during treatment.

You and the person you care for may need more time to decide about treatment once you have all the information. Take the time you need to make the decision that is right for both of you.

Understanding more about treatment options can make it easier to make decisions. Our booklet [Ask about your cancer treatment](#) is for anyone who has been diagnosed with cancer. But it might also be helpful for carers, family members and friends.

Giving consent

Before someone has any treatment, the cancer doctor, nurses and members of the healthcare team will explain the treatment and its side effects. The cancer doctor will usually ask the patient to sign a form saying that they give permission (consent) for the hospital staff to give treatment. No medical treatment can be given without the person's consent.

Before they are asked to sign a consent form, the person you care for should be given information about:

- what the treatment involves
- risks and benefits
- side effects
- any other treatments that may be available.

Or the person's consent can be a spoken agreement with their doctor. Their doctor will record this in their medical notes.

If the person you care for is not able to give consent, they may still be able to have treatment if their cancer doctor thinks it is in their best interests.

We have more information about giving consent on our website. Visit [macmillan.org.uk/treatment-consent](https://www.macmillan.org.uk/treatment-consent)



Capacity

For consent to be valid, the person giving consent must have capacity. This means that they must be able to:

- understand all the information given to them
- remember the information long enough to make a decision
- consider the benefits and risks of treatment
- make an informed decision
- communicate their decision by talking, including using sign language or any other means.

The specialist doctor looking after the person with dementia and cancer may need to assess whether they have capacity.

If someone does not have capacity to make a decision, healthcare professionals can still give treatment if they believe it is in the person's best interests. A best interests decision makes sure that:

- a person's rights are respected
- the decision is the best one for them.

Healthcare professionals will try to understand the person's wishes by getting advice from a partner, family member or friend. If the person does not have family or friends who can help, they must be supported by a special advocate called an Independent Mental Capacity Advocate (IMCA).

This is someone who can act for and support the person through making any decision, such as whether to have serious medical treatment.

[Alzheimer's Society](#) has more information about making decisions and capacity.



Planning ahead

Sometimes, the person you care for may have given you or another trusted person legal power to make decisions for them. This is called [lasting power of attorney \(LPA\)](#). LPAs are permanent and are valid only in England and Wales. There is a different process in Scotland and Northern Ireland.

It can help the person you care for to think ahead before their ability to make decisions is affected. They can write down how they would like to be cared for. It might be helpful for them to give clear instructions about any treatments they would or would not want to have. This is known as making [advance decisions](#).

If you care for someone with cancer and dementia, you may have to help them decide about treatment or make decisions for them. It can be difficult to know what to do. Talk to the dementia specialist doctor or nurse. They can give you advice.

Appointments and hospital visits

If you are the main carer for someone with cancer and dementia, you may need to go with them to their GP and hospital appointments. You may also need to visit the hospital during their treatment.

You may be able to get extra support. Talk to your cancer doctor, nurse or other members of the healthcare team about how they might be able to help you both:

- attend appointments
- cope with treatment
- manage any side effects.

During appointments

The cancer doctor, nurses and any other healthcare professionals may know that the person you care for has dementia. It is sometimes recorded on their medical notes and referral letter. But this is not always the case, so it is important to check that staff know:

- that the person you care for has dementia
- how well they can remember things and understand information
- how to talk to them and include them in discussions and decisions about their care
- their usual routines and preferences
- the level of support they may need.

You may like to support the person with dementia by asking for any difficult information to be explained in a different way. For example, you could ask for a diagram or short, simple, written information. You can take this away and look at it together whenever you need to. With the permission of the person with cancer and dementia, you could ask that copies of any hospital letters are also sent to you.

How can healthcare professionals help?

The healthcare team will want to communicate in ways that are helpful to the person with cancer and dementia. If you think it would help, you could ask the team to:

- give information in a quiet place without distractions
- meet with you both in the same room each time, if possible
- repeat things
- show you both any treatment areas or equipment before treatment starts
- identify a key worker who you can contact with any questions and who can get to know you both.

You can also ask a healthcare professional whether you can record the appointment. Most mobile phones can be used to make an audio recording or voice note. You do not have to record the whole conversation. You can ask the doctor or nurse to make a short summary of what was said at the end.

This means you can later review what was said in the appointment. Or you can pass on any information to family members, if the person with dementia is happy for you to do so.

Getting to appointments

The person with cancer and dementia will usually have many medical appointments. You may need to go with them if you can.

You can ask for things that may make attending appointments easier for you and the person you care for, such as:

- A telephone or video consultation might be possible. This may reduce the number of times you have to travel to and from hospital.
- The person may be able to have treatment at another location or mobile unit close by can reduce travel distance.
- You may be able to reschedule an appointment time to one that suits the person with dementia. For example, an afternoon appointment may be better if they find mornings more difficult.
- Volunteer staff can meet the person with dementia and stay with them while you park the car.
- Hospital transport may be available. It will usually take longer, as more than 1 patient may be transported at a time. If you are supporting the person with dementia, ask to have an escort seat when you book.

Waiting at hospital for appointments can be difficult for some people with dementia. Some healthcare settings may provide quieter waiting areas with books and jigsaws to help pass the time. They may provide areas to get drinks and snacks, so that people do not have to find their way to the cafe or shop. You could also take items such as magazines to keep the person with dementia occupied while you wait.

Hospital admissions

The person you care for may have to stay in hospital, or go to hospital for treatment. It is important that the team looking after them knows about their everyday needs. This might include:

- how they normally communicate
- how they get around
- whether they need any special equipment, such as a hearing aid, walking stick or raised toilet seat
- whether they need help with daily activities such as washing, dressing or eating
- whether they have any special dietary needs
- how they behave when they are in pain.

The [Alzheimer's Society](#) has a template form called 'This is me'. You can download a copy or order a free copy by post. The form is helpful for the person with dementia if they are in an unfamiliar place, such as a hospital ward. It can help if they are having problems communicating. The form can be filled out by people with dementia and their carers.

If the person you care for is going to hospital for a test or treatment, you can ask to be there. Many healthcare settings support '[John's campaign](#)'. This welcomes carers to stay with the person they care for outside of normal visiting hours. This may help the person with dementia to be less stressed or anxious. It also encourages carers to help the healthcare team give care. The specialist nurse, doctor or healthcare team member can talk to you more about this.

We also have more information on talking to the healthcare team at macmillan.org.uk/talk-healthcare-team

**“ I never imagined
I would see an upside
to my husband's
cancer diagnosis.
But I am grateful
it led to the diagnosis
of young-onset
dementia. ”**

Lorelei King, carer for husband with dementia and cancer, and ambassador for Dementia UK



Planning for the future

Planning for the future

26

Care options

30

Planning for the future

If someone has dementia, it is likely that their ability to make decisions (mental capacity) will be affected in the future. There may be a time when they are no longer able to make decisions or communicate easily.

The person you care for may already have an idea of how they would like to be treated at the end of their life. If they are able to plan ahead, it can help you and the healthcare professionals caring for them.

There are different ways the person you care for can plan ahead. This is sometimes known as advance care planning. Usually, this is a chance for them to make decisions about:

- their wishes and preferences for care (advance statements)
- whether there are any treatments they do not want to have (advance decisions or directives)
- whether they want to give other people the legal power to manage their affairs – for example, their health, money and property.

Giving other people the legal power to manage your affairs is called a [power of attorney](#).

[Dementia UK](#) has more information about advance care planning.

If the person you care for identifies as LGBTQ+, this may have an impact on the treatment and care they would like to receive. [Compassion in Dying](#)'s guide **Your treatment and care: Planning ahead for the LGBT community** may be helpful.

Wishes and preferences for care

(advance statements)

The person you care for can talk to you, or to someone else they trust, about how they would like to be cared for. They can also write down their wishes and preferences and share them with family members and healthcare professionals. This is called an advance statement.

Advance statements are not legally binding. But they must be considered when healthcare professionals make decisions about that person's care.

There are different documents that can be used to record wishes and preferences. You can ask a doctor or nurse which documents to use.

Advance decisions and directives to refuse treatment

An advance decision to refuse treatment (ADRT) is sometimes known as an advance decision or advance directive. It is a decision about treatments the person you care for does not want to have. For example, they may decide that if their breathing stops, they do not want treatment to try to bring them back to life (resuscitate them). Or they may decide that if they are very ill and have an infection, they do not want to be given antibiotics.

If the person you care for refuses a treatment, they will still receive good care. They will still have medicines to help manage any symptoms.

Power of attorney

The person you care for can give 1 or more trusted people power of attorney. This is the legal power to make decisions on their behalf. There are different types of power of attorney.

Ordinary power of attorney

A person making an ordinary power of attorney must have mental capacity. This power of attorney is temporary and only used for a set time. For example, it could be used to make financial decisions when a person is on holiday or in hospital.

[Age UK](#) has further information.

Lasting power of attorney (LPA)

There are 2 types of LPA. One relates to health and welfare. The other relates to property and finances. Someone can choose to make 1 type of LPA, or both. An LPA is a legal process set up before a person loses mental capacity. A person with dementia can state what they would like to happen in the future if they lose mental capacity. LPAs are permanent and are valid only in England and Wales. There is a different process in Scotland and Northern Ireland.

[GOV.UK](#) and [Dementia UK](#) have further information about LPAs.

Although someone can create their own power of attorney, it can help to speak to a solicitor. They will make sure it meets all the requirements of the law. If you do not have a solicitor, you can find one by contacting the [Law Society](#).

We have more information on planning for the future. You can find out how to order the following booklets on page 86:

- [Planning ahead when living with cancer – England and Wales](#)
- [Planning ahead when living with cancer – Scotland](#)
- [Your life and your choices: Plan ahead, Northern Ireland.](#)



Care options

If possible, it can be helpful for the person you care for to think ahead and make some decisions about where they want to be cared for in the future. Making decisions about the future can be difficult. Each person's situation will be different. Where they will be cared for depends on:

- what they want
- what help they have from family and friends
- what services are available locally
- their medical condition.

Care at home

Many people prefer to stay at home, if they can, so they can stay in a familiar environment. They can still be surrounded by the people and things that are important to them. Care may be provided by family or friends or paid carers, such as a live-in carer.

If you are caring for the person in their own home, it is important to take a break sometimes. This means letting someone else care for the person you look after for a while. This is called respite care. Respite care options include:

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

Contact your local adult social services department through your [local council](#). You can ask for an assessment of your needs to see what might help you. This is called a [carer's assessment](#).

Residential and nursing homes

Sometimes, it is not possible to meet someone's care needs in their own home. Residential homes and nursing homes offer short-term and long-term 24-hour care. They may also provide different levels of care. A social worker or healthcare worker can explain more about this.

They can give you more information about local care homes and the type of care provided. They may also help you think about how to arrange and pay for different types of care.

Arranging a stay in a care home can take time. Lists of local care homes are available from your local adult social services department. The standard of care provided by care homes and care agencies is monitored across the UK by care regulators.

These include:

- in England, the Care Quality Commission (CQC)
- in Scotland, the Care Inspectorate
- in Wales, the Care and Social Services Inspectorate Wales
- in Northern Ireland, the Regulation and Quality Improvement Authority.

Before choosing a care home or agency, you may want to check its standard of care with one of these organisations. It can be useful to find out whether they are able to meet the needs of someone with cancer and dementia. Your healthcare worker or social worker may be able to give you this information. You can ask to visit the care home before you decide, and talk to staff about how they might meet the needs of the person you support.

Hospices

Sometimes the person you care for may become more unwell or develop symptoms caused by cancer. They may want to be cared for in a hospice or in the palliative care unit of a local hospital.

Their GP, district nurse, specialist community palliative care nurse or social worker may suggest a short stay in a hospice or hospital. This may be because they have symptoms that would be easier to control with specialist care. They may be given treatments until symptoms improve. They then may be able to go back home.

Hospices are generally smaller and quieter than hospitals. They usually 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 hospice care, you can ask to visit before making a decision. Some hospices offer an Admiral Nurse service. You can call Dementia UK's Admiral Nurse Dementia Helpline on [0800 888 6678](tel:08008886678) and they can help you find where these are.

Community palliative care

Palliative care teams include specialist nurses and doctors. These teams specialise in controlling pain and symptoms, as well as offering emotional support. 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. They will tell you more about their services, how to contact them and when they are available.

Dementia UK's Admiral Nurse Dementia Helpline can help carers find out what respite and long-term care options are available.

Emergency replacement care

In an emergency, some local authorities may be able to provide replacement care to the person with cancer and dementia. This is usually for up to 72 hours depending on the situation. You will need to contact the person's [local authority](#) for more information.



Symptoms and side effects

Managing symptoms and side effects

36

Managing symptoms and side effects

The person you care for may have symptoms or side effects caused by cancer or cancer treatment. Symptoms and side effects can usually be prevented or well controlled.

Symptoms or side effects will depend on the type of cancer or treatment. We have more information about the most common side effects in our booklet [Side effects of cancer treatment](#).

The person you care for may not be able to tell you if they have symptoms or side effects. You may have to ask them regularly. If they have problems communicating, it can help to look for signs in their body language, such as restlessness. Or there may be changes in their facial expression, such as frowning.

Some symptoms or side effects of cancer may be like the ones caused by dementia. During cancer treatment, if you are worried about symptoms, always contact the cancer team for advice.

Memory or concentration problems

Some people having treatment for cancer may have:

- memory problems
- difficulty with thinking clearly or concentrating
- extreme tiredness (fatigue)
- low mood.

We have more information in tiredness in our booklet [Coping with tiredness \(fatigue\)](#).

These changes are sometimes called chemo brain. This is because the symptoms were first linked to chemotherapy. But changes in memory and concentration can affect people having other types of cancer treatment.

Memory loss can be a symptom of any type of dementia. People with dementia and cancer are more likely to have this side effect. For some people having cancer treatment, dementia symptoms may get worse temporarily. For others, this change may be permanent.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call us on [0808 808 00 00](tel:08088080000).



Poor appetite and eating problems

Sometimes, cancer and its treatment can cause problems with eating. Some problems are temporary and improve after treatment. Others may last longer. The person you care for may find it more difficult to eat. Problems that can affect eating include:

- loss of appetite
- feeling sick
- being sick
- a sore mouth
- taste changes
- difficulty swallowing
- diarrhoea or constipation.

Having dementia can also have an effect on a person's appetite and their ability to eat and drink.

If you think the person you care for is not eating well, ask their GP, cancer doctor or specialist nurse to refer them to a dietitian. Qualified dietitians are experts in assessing people's food needs. They can look at the person's diet and any special dietary requirements they have. They can give advice on which foods are best for them and whether any food supplements would be useful.

Speech and language therapists (SLTs) can assess for any difficulties with swallowing. They can offer support and advice. If you think the person you care for has problems with swallowing food, ask their GP, cancer doctor or specialist nurse to refer them.

Some cancer treatments can damage the cells that line the mouth or throat. The person you care for may develop a sore mouth, which may cause problems with eating. The healthcare team can prescribe medicines to help with a sore mouth. It is important to follow any advice they give. Any soreness is usually temporary, and usually gets better when treatment ends. You may need to support the person you care for with their mouth care.

Helping a person with cancer and dementia to maintain a healthy diet can be difficult. But it is important to encourage them to eat as well as they can. This can help stop problems such as constipation and dehydration.

If you are able to, you could:

- involve the person in deciding what to eat
- encourage them to eat less saturated fat and sugar, such as cakes, crisps and sweets
- make sure they eat plenty of fruit, vegetables and high-fibre foods to help prevent constipation
- encourage them to drink plenty of fluids during the day – about 2 litres (3½ pints) can help prevent constipation and dehydration
- try foods they can pick up with their fingers, if they find it hard to use cutlery
- help them look after their teeth with regular dental checks, and make sure any dentures fit properly.

We have more information in our booklets:

- [Eating problems and cancer](#)
- [The building-up diet](#)
- [Healthy eating and cancer.](#)

[Dementia UK](#) has information on supporting a person with dementia with eating and drinking and mouth care.



Constipation

Some people with cancer and dementia are more likely to become constipated. It is important for someone with dementia to avoid constipation. This is because it can make them more confused.

The main reason people with cancer and dementia get constipated is that they are not drinking enough. They may also get constipated because they:

- are not eating enough
- cannot move around enough
- are taking painkillers that cause constipation.

Try to encourage the person you care for to drink more fluids and eat more fruit and high-fibre foods. If constipation is a problem, tell their GP, district nurse or specialist nurse. They may recommend medicines to help.

It can help to keep a note of the person's bowel movements. This may help you prevent or treat constipation before it becomes severe or makes them more confused.

Pain

Many people with cancer will have pain at some point in their illness. But for most people, pain can be managed by using non-drug treatments or different medicines, such as painkillers.

Some people with dementia may not be able to tell their carers they are in pain. Look for signs of pain in the behaviour of the person you care for. For example, they may:

- have changes in body language, such as fidgeting or restlessness
- start shouting out
- hold the part of their body that is sore
- change their facial expression or clench their teeth
- become pale or sweaty
- refuse help or care
- become withdrawn
- refuse food or have other changes in appetite.

If you think the person you care for is in pain, it is important that you support them in telling their healthcare team. Different healthcare professionals may be involved in treating and controlling the person's pain.

Non-drug treatments for pain

Sometimes, simple things can help to improve cancer pain.

You could try:

- changing their position
- using heat or cold – for example, a hot water bottle in a cover may help ease aches and stiffness
- asking whether they would like a massage.

It is important to explain what is going on, and to stop if the person seems to be in any discomfort.

Painkillers

Sometimes painkillers are prescribed to help control cancer pain. Painkillers are usually tablets, capsules or liquids taken by mouth (orally). The person you care for may have problems swallowing medicines or remembering to take them. If this happens, their GP, cancer doctor or pharmacist can prescribe other ways to take painkillers, such as patches that stick to the skin.

You could also offer them over-the-counter or prescribed painkillers regularly. You should give these exactly as instructed on the packet. Always check with their GP or cancer team that these painkillers are safe to use with other treatments, such as chemotherapy.

Sometimes the person you care for may need specialist help to assess their pain and symptoms. The doctors and nurses can adjust the dose of medicines or add new ones to control symptoms. Some people may have a short stay in the hospice to do this. Once their symptoms are controlled, they may be able to go home again.

We have more information about pain and ways to manage it in our booklet [Managing cancer pain](#).

[Dementia UK](#) has a leaflet on pain in dementia.



Sleep problems

Both cancer and dementia may cause problems sleeping at night. Feeling very tired during the day can make symptoms of dementia worse.

There are different reasons why someone may not be sleeping well. It can help to look for changes in sleep patterns. If there are changes, try to find out if something is causing them. There may be things you can do to help.

Keeping physically active during the day may help the person sleep at night. If they can do some gentle exercise, you could try doing it with them. For example, you could go on short walks together.

If physical problems such as pain, discomfort or feeling unwell are stopping them from sleeping, talk to their GP, district nurse or specialist nurse. They may be able to give the person medicines that help with the symptoms of cancer or side effects of cancer treatment. You may also be able to get equipment that may make them more comfortable, such as a pressure-relieving mattress.

Some people find that anxiety, worry and emotional distress are keeping them awake at night. To support the person you care for, you could let them know that you are there to listen or talk things through with them.

We have helpful information about starting conversations and listening in our booklet [Talking with someone who has cancer](#). We also have information about sleep problems and advice on how to get a good night's sleep. Visit [macmillan.org.uk/trouble-sleeping](https://www.macmillan.org.uk/trouble-sleeping)

Dementia UK has information on dementia and sleep.

'Sundowning' is when a person's dementia symptoms get worse in the evening, around dusk. [Dementia UK](#) has more information about sundowning and how to cope with the effects.

A man with short brown hair, wearing a teal t-shirt and dark trousers, is looking down at a brochure he is holding. He is standing next to a white information stand. The stand has the text 'MACMILLAN CANCER SUPPORT' printed vertically in green. The stand also has a display of various brochures. The background is a bright, out-of-focus indoor space with large windows.

MACMILLAN
CANCER SUPPORT

Practical help and support

Organising help and services

50

Other sources of help

54

Organising help and services

As a carer, you may feel you have to do everything yourself. Accepting you need help with your caring responsibilities can be a difficult step. But having support can benefit both you and the person you care for.

You can find out the different types of support available by contacting your local adult social services department. You can search for your local council online (page 100). The person's GP can also make a referral. The [Dementia UK Admiral Nurse Dementia](#) Helpline and Carers Trust can also help.

If the person you care for is coming home from a stay in hospital, any help and services they need are usually organised by a hospital discharge co-ordinator. This is to make sure that you can both safely manage before the person you care for comes home. Sometimes you may have more assessments to check what kind of ongoing care the person needs at home. If you have any questions, speak to the person's GP or the community health or social team.

Holistic needs assessment

The person you care for may have a holistic needs assessment (HNA) before they come home. This is a separate assessment that is only for people with cancer. In the assessment, you will both be asked questions about how you are feeling and what help you need. This is to make sure you get the right support.

You and anyone else involved in the person's care should get a copy of the completed assessment form, including their GP. You can ask the person's key worker, such as a clinical nurse specialist (CNS), about this.

We have more information about HNAs in our leaflet [Holistic Needs Assessment: Planning your care and support](#).

Planning for hospital discharge

If there are lots of things to discuss before someone leaves a hospital or hospice (is discharged), the healthcare team may arrange a meeting. This may involve:

- the person receiving care and their main carer
- the doctor in charge of the person's care
- specialist nurses
- an occupational therapist
- a social worker.

If you are the main carer, you and the person with cancer and dementia should be involved in any discharge planning as early as possible. Health and social care professionals will work with you both to decide a plan. This is to make sure that the person has the right support when discharged from hospital.

If you have any questions, talk to the nurses or ward manager. They are there to support you both. They can also arrange for you to meet with a social worker about any help you may need. This is called a carer's assessment. If you are not happy with anything that has been arranged, let them know.

Tips for planning a hospital discharge

The following tips may help when planning for a hospital discharge:

- If you find it difficult to discuss your needs with the hospital staff, write down everything you want to discuss.
- Remember that plans can be changed if the situation changes. For example, you may need help later on with the person's personal care, such as washing or dressing.
- The person you care for should be given information from the hospital or hospice to take home. This may tell you what medicines and diet they need, as well as where to get more support. If the information is not clear, ask for more details. You have the right to ask any questions you want.
- When the person you care for is discharged, make sure they have all the medicine they need. You will need enough to last until a new prescription can be arranged by the GP. You can talk to the hospital staff about this.

Carer's assessment

As a carer, you can ask the social worker for an assessment of your needs. This is called a carer's assessment. It gives you the chance to talk about any help you need.

Even if the person you care for does not qualify for support, you can ask for this assessment. You may be able to get support with respite breaks and help to look after the person you care for. We have more information in our booklet [Looking after someone with cancer](#). It is important to keep healthy and to balance caring with your life, work and family commitments.

If you have been assessed as needing social services, you may be able to get direct payments called Carer's Allowance from your local authority. This means you are given money to organise care services yourself, instead of local social services organising and paying for them directly. You can ask your local council for more information about direct payments. Or you can visit gov.uk/carers-allowance for more information.

Other sources of help

You do not have to cope with caring for someone on your own. Building a support network of friends, family or neighbours can make a big difference. 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
- how the services are organised in your area.

GPs

A GP looks after people who are unwell and being cared for at home. They will assess the person you care for. They can refer the person to other services, such as:

- district nurses
- community palliative care nurses
- social workers
- occupational therapists
- physiotherapists
- speech and language therapists
- dietitians
- community mental health services.

If needed, they can help arrange for the person you care for to go into a hospital, nursing home or hospice.

District nurses

District nurses work closely with GPs. They can give advice and support to people by visiting them at home.

Specialist nurses

Specialist nurses can give information about and support for certain diseases, such as cancer or dementia. Most specialist nurses work in NHS hospitals or in the community.

Specialist nurses do not usually provide nursing care. But they will:

- assess needs
- give advice
- help people understand their treatment options.

Many Macmillan professionals are nurses who have specialist knowledge of a certain type of cancer. You may meet them if you attend clinic or hospital appointments with the person you care for.

Admiral Nurses

Admiral Nurses provide the specialist dementia support that families need. When things get challenging or difficult, Admiral Nurses work alongside people with dementia and their families to offer one-to-one support and expert guidance.

Admiral Nurses work in:

- local community services
- GP practices
- NHS hospitals
- care homes
- hospices.

They also run [Dementia UK's helpline](#), Closer to Home dementia clinics and virtual clinics.

Social workers

A social worker is responsible for assessing what practical and social help the person you care for needs. They are sometimes called a care manager.

If the person does not already have a social worker, the GP, nurse or hospital staff can arrange a referral. Or you could contact the local social services department. You can find them online under the name of your:

- local authority
- council
- health and social care trust.

The social worker will visit the person you care for and do a community care assessment or needs assessment. Each local authority does its own tests to decide what help they can offer. This means the services offered will vary from area to area.

The hospital social worker can give you information about social services and benefits that the person you care for may be able to claim. These might include services such as meals on wheels, a home helper or help paying hospital travel costs.

The social worker can also do an assessment of your needs as a carer. This is called a [carer's assessment](#).

Physiotherapists

A physiotherapist can help if the person you care for is unsteady on their feet or needs help moving around. They give help and advice on exercises and ways to keep the person as mobile as possible. You could ask their GP or specialist nurse for a referral.

Occupational therapists

Occupational therapists can provide information, support and aids to help people to manage their everyday activities. They can provide support with rehabilitation and memory loss as well as helping to adapt the person's environment.

Dietitians

Dietitians are qualified healthcare professionals who give specific advice to people with eating, dietary or weight problems. They also give advice on healthy eating in general. Some dietitians have specific training in helping people affected by cancer.

Speech and language therapists

Speech and language therapists (SLTs) treat and support people who have problems communicating, eating and drinking.

Specialist continence nurses

People with dementia may already have problems controlling their bladder and bowels (incontinence). Some cancer treatments may make this worse. The person you care for can be referred to a specialist continence nurse. Continence nurses carry out assessments and support people with ways to manage incontinence. You can ask the GP, specialist cancer nurse or practice nurse of the person you care for to refer them.

Help at home

The person you care for may be able to get help in the home. This can support them to stay independent and in their own home. It can also give you a break from caring.

Care attendants, carers or personal assistants come to the home to help. The support and services available are different across the UK. The type of help they give may include:

- personal care, such as washing and dressing
- doing some jobs around the house
- staying with the person so you can have a break.

You usually have to pay towards the cost of services. The person's GP or social worker can talk to you more about this. They can also let you know what help is available in your area.

Voluntary organisations and charities

Voluntary organisations and charities offer various kinds of help. This may include:

- information
- loans of equipment
- grants
- transport
- help with filling out forms or making telephone calls to get relevant support.

Some organisations have volunteers who offer short periods of respite care to give you a break during the day. Others, including [Marie Curie](#) and [Age UK](#), provide befriending services for people who are on their own. They can introduce you and the person you care for to a trained volunteer, who may be able to give one-to-one help and support.

The district nurse, specialist nurse or GP can tell you how to contact these organisations. They will also be able to tell you about the types of help and support available in your area.



Living with cancer and dementia

Looking after everyday health

62

Looking after everyday health

It is important for someone with cancer and dementia to look after their general health as much as possible. This can help prevent some problems in the future and may give them back a feeling of control. You might find the following tips useful:

- Help them to take medications as prescribed. You can ask the pharmacist to put their medicines in a pill organiser (dosette box). Pills are placed in individual boxes marked with the day and time to take them.
- Encourage them to have regular check-ups with their GP or practice nurse. If they feel unwell, try to get them to visit the GP promptly.
- Help them keep up to date with checks on their hearing, eyesight and teeth, to find any problems early.
- Public health experts and cancer specialists have agreed that people living with cancer should receive the coronavirus (covid) vaccine. They may be offered the flu vaccine at the same time. Help them talk to their healthcare team about getting vaccinated. If you are a carer for someone who has cancer, it is important to keep up to date with any vaccines.

[Dementia UK](#) has more information about the covid vaccine and people living with dementia.

Eating well and keeping to a healthy weight

It is important for someone with cancer and dementia to try to eat well and maintain a healthy weight. We have some tips on [managing eating problems](#) in someone with cancer and dementia. We also have some general information about healthy eating in our booklet [Healthy eating and cancer](#) (page 86).

Keeping active

Being physically active can be good for the person you care for. It can help improve symptoms such as:

- tiredness
- a poor appetite
- constipation
- low mood.

It may also reduce stress and help them sleep better.

Check with their GP, cancer doctor or specialist nurse if there are any physical activities the person with cancer and dementia should not do.

Encourage them to start slowly and gradually do more. To begin with, try to reduce the amount of time they spend sitting or lying down. Just moving around the house and doing simple everyday things will help.

We have more information on physical activity in our booklet [Physical activity and cancer](#).

If they can manage short walks or gentle stretching exercises, you could help them do this. Younger people with dementia (young onset dementia) may be able to do more physical activity.

You could check if there are any exercise classes in their area.

[Age UK](#) runs exercise classes in some areas of the UK. It also has physical activity videos to use at home, which you may find helpful.

Alcohol and tobacco

People with dementia may enjoy an alcoholic drink sometimes. But they can become more confused after drinking alcohol, so you may need to limit how much they have. They may need help remembering how much they have already had.

It is not advisable to drink alcohol with some medicines. Check with the GP or pharmacist whether it is safe for the person you care for to have alcohol. People whose dementia is linked to drinking too much alcohol in the past are advised not to drink alcohol.

Stopping smoking is the single most important thing someone can do for their health. Smoking can increase the risk of bone thinning (osteoporosis), some cancers and heart disease.

We have more information on stopping smoking at [macmillan.org.uk/stop-smoking](https://www.macmillan.org.uk/stop-smoking)

During cancer treatment, stopping smoking may help the treatment work better. It can help the body respond to the treatment and heal more quickly. It may lower the risk of certain cancers coming back after treatment.

Memory problems

Memory problems caused by dementia can be different for each person. Someone who also has cancer may need help remembering treatment plans or ways to manage symptoms. Some treatments have specific advice. For example, you may need to help the person you care for remember if they:

- should not eat certain types of food while on treatment
- need to be careful to avoid infection
- have side effects, such as constipation, so they can let their healthcare team know
- need to take cancer medicines in addition to their usual everyday medicines.

We have a range of easy read cancer information (page 86). This can be useful if you want information that is easier to understand.

“ When a patient has dementia, you can't simply leave pills and expect them to know what to do. I set an alarm for his medication to make sure he had taken them. ”

Lorelei King, carer for husband with dementia and cancer, and ambassador for Dementia UK



Caring for someone with cancer and dementia

Being a carer	69
Look after yourself	70
Caring for someone with advanced cancer and dementia	73

“ My mother was unable to understand her cancer diagnosis due to her advanced dementia. ”

Andrew, whose mother was diagnosed with cancer and dementia

Being a carer

You are a carer if you give any unpaid help and support to someone who could not manage without your help. It can include:

- emotional support
- help with daily tasks
- driving them to appointments
- helping with personal care, such as bathing and dressing.

Looking after someone with cancer and dementia can be rewarding. But the physical and emotional demands can be difficult. You may have a lot of different emotions. Getting support and having someone to talk to about how you feel might help you cope.

Dementia UK has more information to support carers with the issues they have to deal with when looking after a person with dementia (page 93).

We also have more practical information and advice in our booklet [Looking after someone with cancer](#), which you may find useful.

Look after yourself

It is important to look after yourself as well as the person you care for. Taking the time to focus on your own health and well-being will also benefit the person you care for. Here are some ways you can do that.

Take care of your health

You can take care of your general health by:

- telling your GP practice that you are a carer so they can give you support and advice
- going to all your health and screening appointments
- getting important vaccinations – if you are the main carer, you may get free flu and coronavirus (covid) vaccinations (jabs).

Talk about your feelings

Finding out the person you care for has both cancer and dementia can be very upsetting. It is common to feel shocked, frightened or angry about their situation.

Talking to other people about how you feel can be helpful.

Some people find it hard to talk to family and friends. Ask your GP to refer you to a counsellor or support group. Or the cancer team may be able to refer you to support at hospital.

If you need more support, you can call the [Macmillan Support Line](#). Or you can call Dementia UK's [Admiral Nurse Dementia Helpline](#).

Take regular breaks

If you are caring for someone, it is important to take breaks if you can. You could:

- accept help from others or ask for help
- do something you enjoy, like reading or going for a walk.

Eat well and stay active

- Try to eat healthy food and sit down to eat a cooked meal.
- If you are tired, ask a family member or friend to help make meals in advance. Try to get out of the house every day and do some gentle exercise, like walking. This can help you feel less tired and stressed.
- If you enjoy sport or going to the gym, try to keep doing this.

Try to relax

- Try relaxation techniques using simple breathing and relaxation exercises. You can use online apps or podcasts. Or your local library may have CDs for you to borrow. You can also ask a healthcare professional for advice.
- Try having a massage or another relaxing therapy that you enjoy. Your local carers' centre or [Macmillan Information and Support Centre](#) may offer free therapies for carers.

Get enough sleep

Many people say that when they are caring for someone who is very ill, they find it difficult to relax at night. You may stay awake thinking and worrying about the person you care for. Or they may be having a bad night, which can also keep you awake.

If you are having difficulty sleeping, avoid watching TV or using a computer before bed. We have more information about trouble sleeping and things that may help on our website.

Visit macmillan.org.uk/trouble-sleeping

Support from other carers

Many people find it helpful to share their caring experience with someone in the same situation. If you feel this way, there are [groups, organisations and healthcare professionals](#) that can help you.

Support groups led by carers

Other carers may understand what you are going through. You could ask a member of your healthcare team what support is available locally.

Online support groups or chat rooms

On our [Online Community](#), you can chat anonymously to other people looking after someone with cancer. Our cancer support specialists can help you find out what is available in your area. Call them on [0808 808 00 00](tel:08088080000).

The [Alzheimer's Society](#) also has an online forum just for those caring for someone with cancer and dementia. You can also get information and advice from [Carers UK](#) or [Carers Trust](#).

Caring for someone with advanced cancer and dementia

If the person has recorded their preferences for [future care](#), this can help you and the person's care team make decisions about what might be best for them at this stage. For example, this may include how and where they would prefer to be cared for, or the things that are important to them.

Palliative care

For some people, it may not be possible to control the cancer any longer. Or they may not be well enough to have treatment. If this happens, their cancer doctor or specialist nurse will make sure they have treatment to manage their symptoms. This is called palliative care.

Some people may already be having palliative care when they are diagnosed with cancer and dementia. Others may be referred to a palliative care team at a later stage. The person you care for can be referred for palliative care by their cancer doctor, GP or specialist nurse.

Community specialist palliative care teams

Palliative care teams include specialist nurses and doctors. These teams specialise in controlling pain and symptoms, as well as offering emotional support. 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. They will tell you more about their services, how to contact them and when they are available.

End of life

Learning that the person you care for may be near the end of their life can be very difficult and distressing. You may experience strong emotions. You may need some time on your own. Or you might want to talk things through with your partner, a relative or a close friend.

Some people find it easier to talk to someone outside their family. If you think this would be helpful, you can talk to your doctor. They may be able to refer you to a counsellor. Or you can contact the British Association for Counselling and Psychotherapy (page 95). They have information about counsellors in different areas and charities that may offer free or discounted counselling.

We have more information about coping at the end of life in our booklet [△ guide for the end of life](#). It is meant for people in the final stages of life, and their carers.

Dementia UK also has information about understanding the changes in dementia and end of life care. You could also contact the Dementia UK [Admiral Nurse Dementia Helpline](#) for support and advice.

“There is still a lot to be done to ensure that the needs of patients with dementia and cancer are met. It is not enough to know that a patient has dementia. There needs to be a clear plan in place as to what having dementia and cancer means in relation to a person's care. ”

Lorelei King, carer for husband with dementia and cancer, and ambassador for Dementia UK



Work, money and benefits

Working and caring	78
Financial help and benefits	79

Working and caring

Balancing working and caring can be difficult. If you need to be at home more than before, you may need to make some decisions about work. You might think about stopping work or working part time to look after someone. This could affect your life in different ways. Stopping work could:

- affect your finances
- make you feel isolated from friends at work
- mean that you cannot keep your skills up to date.

If you can, it is important to talk to the person you care for and involve them in any decisions.

You may find it helpful to find out more about your rights as a carer and an employee before making any decisions. We have lots of information in our booklet [Working while caring for someone with cancer](#).

This includes helpful advice on:

- flexible working
- getting support at work
- talking about cancer in the workplace.

Remember you can ask your local social services for a [carer's assessment](#). This is a chance to talk about any support that would help you balance work and caring, as well as other issues.

Financial help and benefits

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. If you have to stop working or reduce your hours, your income may drop.

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

You can get more information from our money advisers. Call on **0808 808 00 00**.

[Dementia UK's Admiral Nurses](#) can also give financial advice to people affected by dementia.

Carer's Allowance

Carer's Allowance is a weekly benefit for people who look after someone for at least 35 hours a week. It is the main benefit for carers.

If there is more than 1 carer looking after the person, the main carer should apply. Only 1 person can get Carer's Allowance.

Carer's Credit

Carer's Credit helps stop gaps in your National Insurance record if you stop working while you are caring for someone else. It can also help if you are not paying National Insurance because you need to reduce your hours. You may need to pay National Insurance to qualify for a state pension. Visit [macmillan.org.uk/pensions](https://www.macmillan.org.uk/pensions) for more information.

Other benefits

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

- Universal Credit, if either of you has a low income or is 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
- Attendance Allowance if they are aged 65 or above.

You or the person you care for may be able to claim Personal Independence Payment or Attendance Allowance if they have problems looking after themselves or moving around. People who are not expected to live longer than 12 months can make a claim under the special rules for these disability benefits. This means they may receive payments sooner.

You may also be able to get help with travel costs and be eligible for an income tax refund. Our booklet [Looking after someone with cancer](#) has more detailed information about how to apply for these benefits (page 86).

[Dementia UK](#) has a leaflet called **Financial and legal sources of support and advice**. It explains the tax exemptions and financial sources of support available to people looking after someone with dementia.

Council Tax reduction

Some people with dementia may be entitled to a reduction in their Council Tax, or be exempt from paying. Also, some carers do not have to pay Council Tax if they are living with and caring for a person with dementia who gets the higher rate of Attendance Allowance or Personal Independence Payment.

Grants

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

Call the Macmillan Support Line free on [0808 808 00 00](tel:08088080000), 7 days a week, 8am to 8pm.



Insurance

Some life insurance policies pay out when someone is diagnosed with cancer. Read 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 card payments
- mortgage payments.

Macmillan has expert money advisers who can help you understand your insurance policies. You can call them on [0808 808 00 00](tel:0808 808 00 00).

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](#) or [Advice NI](#) can give you advice and information about renting.

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 they may 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.

More information

We have more information about these benefits and ways to get financial support in our booklet [Help with the cost of cancer](#). Or you can call our [money advisers](#) for more guidance and support.

We have a benefits calculator to help you find out what you might be able to get. Visit [macmillan.org.uk/benefits-calculator](https://www.macmillan.org.uk/benefits-calculator)

We also have more information about managing finances on our website. Visit finance.macmillan.org.uk

[Dementia UK](#) has information and advice for anyone affected by dementia, including:

- financial benefits that you may be able to claim
- details of services and organisations that can support you.





Further information

About our information	86
Other ways we can help you	88
Other useful organisations	92
Your notes and questions	104

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.macmillan.org.uk or call us on [0808 808 00 00](tel:08088080000).

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

Online information

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

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at informationproductionteam@macmillan.org.uk or call us on [0808 808 00 00](tel:08088080000).

The language we use

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

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

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

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

- help with any medical questions you have about cancer or your treatment
- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on [0808 808 00 00](tel:08088080000). Or visit macmillan.org.uk/support-line to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

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

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

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

Macmillan Information and Support Centres

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

Find your nearest centre at macmillan.org.uk/informationcentres or call us on [0808 808 00 00](tel:08088080000).

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

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

Help accessing benefits

You can speak to our money advisers for more information. Call us free on [0808 808 00 00](tel:08088080000). Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Support for dementia

Alzheimer's Scotland

Helpline **0808 808 3000**

www.alzscot.org

Provides a range of services for people with dementia and their carers, including personalised support services, community activities, information and advice.

Alzheimer's Society (England, Wales and Northern Ireland)

Dementia Support Line **0333 150 3456**

www.alzheimers.org.uk

Provides a free helpline, and written information about dementia, treatment and living with dementia. Use the dementia directory to find local support services for people with dementia and their carers in England, Wales and Northern Ireland. Use the online community to share experiences with other people affected by dementia.

Dementia UK

Helpline **0800 888 6678**

www.dementiauk.org

Provides practical and emotional information and support to people with dementia and anyone affected by dementia. Services include a free helpline staffed by dementia specialist Admiral Nurses who provide information, advice and support with any aspect of dementia, including Alzheimer's disease. You can also book a virtual clinic appointment to discuss any questions or concerns with an Admiral Nurse by phone or video call at a time that works for you.

Relish

www.relish-life.com

Offers products, activities and well-being resources for people with dementia.

General cancer support organisations

Cancer Black Care

Tel **0734 047 1970**

www.cancerblackcare.org.uk

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**

www.cancerfocusni.org

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

Cancer Research UK

Helpline **0808 800 4040**

www.cancerresearchuk.org

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

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

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

Maggie's

Tel **0300 123 1801**

www.maggies.org

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

Support for carers

Carers Trust

Tel **0300 772 9600**

www.carers.org

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

Carers UK

Helpline **0808 808 7777**

www.carersuk.org

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

John's Campaign

Tel **0124 523 1898**

www.johnscampaign.org.uk

Campaigns for the right of people with dementia to be supported by their family carers. Provides information, support and personal stories through articles, books, videos and a blog. Also shares the ways you can get involved.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**

www.psychotherapy.org.uk

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

Emotional and mental health support

Mind

Helpline **0300 123 3393**

www.mind.org.uk

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

Samaritans

Helpline **116 123**

Email **jo@samaritans.org**

www.samaritans.org

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

Support for older people

Age UK

Helpline **0800 678 1602**

www.ageuk.org.uk

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

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**

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.

Living Made Easy

Helpline **0300 123 3084**

www.livingmadeeasy.org.uk

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

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**

www.lgbt.foundation

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

OUTpatients

www.outpatients.org.uk

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

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**

Textphone **028 9 031 1092**

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

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317**

www.gov.uk/carers-allowance

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

Citizens Advice

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

England

Helpline **0800 144 8848**

www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**

www.cas.org.uk

Wales

Helpline **0800 702 2020**

www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales. Also provides information on lasting power of attorney.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland). You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

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

The Law Society

www.lawsociety.org.uk

Provides details of local solicitors through the 'find a solicitor' feature on their website.

Law Society of Scotland

www.lawscot.org.uk

Law Society of Northern Ireland

www.lawsoc-ni.org

Money Advice Scotland

www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Offers advice on benefits if you live in Northern Ireland.

NI Direct

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **0344 892 0902**

www.nihe.gov.uk

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

StepChange Debt Charity

Tel **0800 138 1111**

www.stepchange.org

Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**

www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Advanced cancer and end of life care

Compassion in Dying

Helpline **0800 999 2434**

www.compassionindying.org.uk

Provides support for making informed choices and starting honest conversations about death and dying. Also provides guides on setting up a will, power of attorney and advance statement.

Hospice UK

Tel **0207 520 8200**

www.hospiceuk.org

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

Marie Curie

Helpline **0800 090 2309**

www.mariecurie.org.uk

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

The Natural Death Centre

Helpline **0196 271 2690**

www.naturaldeath.org.uk

Offers independent advice on aspects of dying, funeral planning and bereavement.

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team in partnership with Dementia UK. It has been approved by members of Macmillan's Centre of Clinical Expertise.

With thanks to: Professor Laura Ashley, Professor of Health Psychology; Fiona Chaabane, Clinical Nurse Specialist and Consultant Admiral Nurse; Dr Karen Harrison Denning, Head of Research and Publications; Dr Rachael Kelley, Reader in Dementia Research; Professor Claire Surr, Professor of Dementia Studies, Director of the Centre for Dementia Research Leeds Beckett University; and Jeni Woods, Occupational Therapist.

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

We welcome feedback on our information. If you have any, please contact informationproductionteam@macmillan.org.uk

Sources

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

Caring for people with dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy). May 2020. The Society and College of Radiographers. Available from: <https://www.sor.org/Learning-advice/Professional-body-guidance-and-publications/Documents-and-publications/Policy-Guidance-Document-Library/Caring-for-People-with-Dementia-a-clinical-practic> [accessed June 2023].

Surr CA, Kelly R, Griffiths AW, Ashley L, Cowdell F, Henry A, et al. Enabling people with dementia to access and receive cancer treatment and care: the crucial role of supportive networks. *Journal of Geriatric Oncology*. 2020;11(7): 1125–1131. Available from: <https://doi.org/10.1016/j.jgo.2020.03.015> [accessed July 2023].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer.

They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

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

5 ways you can help someone with cancer

1. Share your cancer experience

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

2. Campaign for change

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

3. Help someone in your community

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

4. Raise money

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

5. Give money

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

Valid from Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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



This booklet is about cancer and dementia. It is for anyone who cares for a friend or family member who has both cancer and dementia.

The booklet includes information on how to get support and look after yourself.

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

For information, support or just someone to talk to, call **0808 808 00 00** or visit [macmillan.org.uk](https://www.macmillan.org.uk)

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

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

Trusted
Information
Creator



Patient Information Forum