

Cancer and dementia: a guide for carers



In partnership with



DementiaUK
Helping families face dementia

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.

Managing two conditions 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.

For more information

We have produced this booklet in partnership with Dementia UK. For more information about different types of dementia, you can call Dementia UK on **0800 888 6678**. There is also information on their website – visit **dementiauk.org** Read more about how Dementia UK can help you on page 87.

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

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

If you are deaf or hard of hearing, call us using 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**.

Quotes

In this booklet, we have included quotes from people who have chosen to share their story with us and Dementia UK. Some are from our Online Community (**macmillan.org.uk/community**). To share your experience, visit **macmillan.org.uk/shareyourstory**

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

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UNDERSTANDING CANCER AND DEMENTIA

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About cancer and dementia

Each year, about 363,000 people in the UK are diagnosed with cancer. And about 850,000 people in the UK are living with dementia. Many people with dementia are also living with other health conditions, including cancer.

Many people with dementia are cared for at home by a family member or friend. In the UK, there are about 670,000 carers of people with dementia.

The main risk factor for both cancer and dementia is age. Most people with dementia are over 65 years old. About half (50%) of people diagnosed with cancer are over 70 years old.

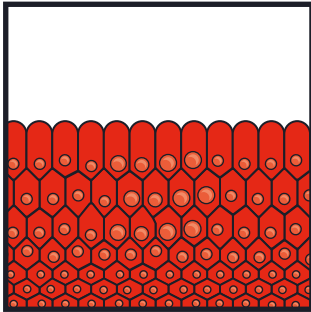
If you care for someone who has both cancer and dementia, it can be very difficult for you and the person you care for.

What is cancer?

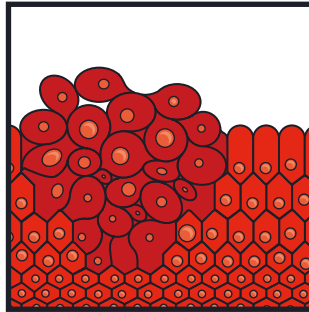
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Normal cells



Cells forming a tumour



Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

Some types of cancer start in blood cells. Abnormal cells can build up in the blood and in the bone marrow, where blood cells are made. These types of cancer are sometimes called blood cancers.

Treatments for cancer

The main treatments for cancer are:

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

The treatment depends on:

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

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Treating cancer in someone with dementia

The cancer treatment offered to the person you care for will depend on their individual situation. But it will also depend on the stage of the dementia. Doctors and nurses who specialise in cancer can talk to you about which cancer treatments might help.

Benefits and disadvantages of treatment

Some people with cancer and dementia will be offered the standard treatment for the cancer. They may sometimes have to spend time in hospital.

The person you care for is likely to have side effects from cancer treatment. These are usually temporary and can be controlled with medicines. But some people have longer-lasting side effects known as late effects. We have more information on the late effects of cancer treatment at macmillan.org.uk

For some people, treatment will cure the cancer. Other people may not respond to the treatment. This means some people may have the side effects of treatment without any of the benefits.

Some people may not have standard treatment. This may be because they are not well enough or have other health problems. Some people may choose not to have the standard treatment. Instead, they may have other treatments with:

- lower doses of medicine
- fewer treatment sessions.

They will usually spend less time in hospital and have fewer side effects. These types of treatment are given to control the cancer, but they will not get rid of it completely.

Sometimes the treatment stops working. If this happens, the person receiving it can still be given supportive or palliative treatment to help control symptoms. The person you care for may also choose to stop treatment at any time. If they do, they will still be offered supportive treatments.

Some people may choose not to have treatment for the cancer but go straight to palliative care. If someone is having problems with symptoms or side effects, they can have supportive treatments for any stage of cancer.

Making decisions

Talk to the person you care for about if they would like to have treatment and what they might prefer. It may be helpful for you to go with them to talk to their doctor about treatment options. You may also be able to talk about the possible benefits and side effects of treatment with a nurse.

When someone has dementia, it can be useful to think ahead about how that may affect treatment. It is also important to think about how cancer treatment might 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 that the person must lie very still during treatment.

You may be able to get extra support to cope with treatment or any side effects that cause a problem. Talk to your doctor or nurse about how they might be able to help. You and the person you care for may need more time to decide once you have all the information.

Giving consent

Before someone has any treatment, their doctor will explain the aims of the treatment. They will usually ask them 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 full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If the person you care for is not able to give consent, they may still be able to have treatment if their doctor thinks it is in their best interest. We have more information about consent on pages 16 to 17.

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 for a specific time
- consider the benefits and risks of treatment
- make an informed decision.

Some people with dementia do have the capacity to make informed decisions. For others, the ability to make specific decisions can be affected. The specialist doctor looking after them may need to check if they can make an informed decision about treatment. They may use a hospital assessment to do this.

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

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

If someone is not able to make a decision, health professionals can still give treatment if they believe it is in the person's best interests. But they must try to get advice about the person's wishes from a partner, family member or friend. If the person with dementia does not have family or friends who can help, they may be referred to an independent advocate. This is someone who can support and act for the person through making any decision, such as whether to have serious medical treatment. The Social Care Institute for Excellence (SCIE) has more information on independent advocates (see page 95).

The person you care for may have given someone legal power to make decisions for them. This is called lasting power of attorney (see pages 26 to 27). 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 is helpful to give clear instructions about any treatments they would or would not want to have. This is known as making advance decisions (see page 25).

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.

Alzheimer's Society (see page 86) has a fact sheet called **Making decisions and managing difficult situations** that you may find useful.

Appointments and hospital visits

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

During appointments

During appointments, you can help by remembering and writing down information. You can also help the person you care for describe any symptoms or problems they are having. If they had any questions before the appointment, you can prompt them and help them to remember what they wanted to ask.

The cancer doctor, nurses and any other health professionals should know that the person you care for has dementia. It is usually recorded on their medical notes and referral letter. But it can be useful to explain what this means – for example, how well the person you care for can remember things and take in information. It might also be helpful to say if they have lots of other appointments or hospital visits for dementia.

You can ask the doctor or nurse to communicate in ways that are helpful. It might help if the health professional:

- faces the person you care for, at the same level
- gives information in a quiet place without distractions
- makes eye contact when talking
- keeps information simple by avoiding medical words
- repeats things if necessary
- breaks information down into small chunks that are easy to understand.

You can also ask the doctor or nurse if you can record the appointment. This means you can go back over what was said later. This can help with making decisions about treatment. It may also be reassuring, and you can pass it on to other family members if they want to know more. 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.

Hospital admissions

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

- 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.

If the person you care for is going to hospital for a test or treatment, you can ask to be there. For example, you may be able to help keep them calm or still during a scan or while they are having treatment through a drip. This may not be suitable for all types of test or treatment. Ask the doctor or nurse if it is possible. Or you could check with the department that the appointment is at. Some hospitals may allow you to visit outside usual visiting hours if it helps to keep the person you care for stay calm.

Alzheimer's Society has an information form called **This is me** (see page 86). It can be filled out by people with dementia and their carers. The form is helpful for the person with dementia if they are in an unfamiliar place, such as a hospital or respite care. It can help if they are having problems communicating.

We have more information on talking to healthcare staff at macmillan.org.uk

Getting to appointments

Sometimes getting to and from hospital can be difficult and expensive – especially if the person you care for needs help to move around. Here are some things you could do to try and make this easier:

- Ask for a telephone consultation. This will not always be possible, but it may reduce the number of times you have to get to and from hospital.
- Use hospital transport. Hospital transport may vary. It will usually take longer, as more than one patient will be transported at a time. Ask the nurse what is available. Or phone the department where the appointment will be.
- Specialised driving services for elderly or disabled people are available in some areas. They will charge a fee for this service.

Waiting at hospital for appointments may be more difficult for someone with dementia. It can help to take something they enjoy to pass the time, such as:

- books
- magazines
- puzzles
- a twiddle muff.

A twiddle muff is a knitted hand muff with objects of different textures such as beads, buttons or ribbons to keep the person's hands occupied.



PLANNING FOR THE FUTURE

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Planning for the future

If someone has dementia, it is likely 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 health 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 an opportunity 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) – this is called a power of attorney.

If the person you care for identifies as LGBT, this may have an impact on the treatment and care they would like to receive. An organisation called Compassion in Dying has written a guide called **Your treatment and care: Planning ahead for the LGBT community** that may be helpful (see page 95).

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 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 doctors to try to bring them back to life (resuscitate them). Or 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 they may have.

Power of attorney

The person you care for can give one or more other people power of attorney. This is the legal power to manage their affairs. This can be temporary or permanent. A temporary power of attorney is only for a set time. For example, it could be while the person is staying in a care home. It stops when the set time ends or if the person decides to cancel it.

A permanent power of attorney may be used if the person you care for thinks they may lose the ability to make decisions for themselves. Depending on where in the UK the person you care for lives, it is called:

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

When someone is given a permanent power of attorney, they can make decisions about another person's property and finances or health and welfare.

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 (see page 94).

We have more information on planning for the future in our booklets **Planning ahead for end of life** for England, Wales and Scotland and **Your life and your choices: plan ahead** for Northern Ireland (see page 82). Dementia UK has a leaflet on lasting power of attorney which you may find useful (see page 87).

I think mum does still have the capacity to make decisions. Her dementia isn't so advanced.

Keely, Online Community

Care options

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. They may be able to stay at home with help and support. Or they can be cared for in a hospice or nursing home.

Where they will be cared for depends on:

- what they want
- what help they have from family and friends
- what services are available in the area they live
- their medical condition.

Most people prefer to stay at home if they know they will have good-quality care. Even if they choose not to be cared for at home, they can still be surrounded by people and things that are important to them.

Short-term care

If the person you care for decides to be looked after at home, they can still have some types of short-term care. For example, they may be able to go to a day centre if you work during the day or need a break from caring. Hospices and residential homes may also offer short stays for a few days or weeks. This might be for specialised care that helps control symptoms, or to give you a break from caring.

Their GP, district nurse or specialist palliative nurse may be able to arrange short-term care in a:

- hospital
- residential home
- care home with nursing (nursing home)
- hospice.

Care in residential homes or nursing homes

Residential homes and nursing homes offer short-term and long-term care. They may also provide different levels of care. A social worker or healthcare worker can explain 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 pay for different types of care
- how to arrange different types of care.

Arranging a stay in a care home can take time.

Lists of local care homes are available from your local social services department. The standard of care provided by care homes and care agencies is monitored across the UK by care regulators.

These include:

- The Care Inspectorate Scotland
- The Care and Social Services Inspectorate Wales
- The Care Quality Commission (CQC)
- 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 (see page 89). It can be useful to find out if 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 could also ask to visit the care home before you decide.

Hospice care

Sometimes the person you care for may become more unwell or develop symptoms caused by cancer. They may want to be looked after in a hospice or in a palliative care unit of the 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 one before making a decision.

Dementia UK's Admiral Nurse Dementia Helpline can help carers find out what respite and long-term care options are available. Call them on **0800 888 6678** or send an email to **helpline@dementiauk.org**

SYMPTOMS AND SIDE EFFECTS

Managing symptoms and side effects

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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 booklets **Managing the symptoms of cancer** and **Side effects of cancer treatment** (see page 82).

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 or facial expressions.

Some symptoms or side effects of cancer may be like the ones caused by dementia. If the person you care for has symptoms you are worried about, talk to the doctor or nurse.

Memory or concentration problems

Some people having treatment for cancer may have:

- memory problems
- difficulty concentrating
- feelings of extreme tiredness.

This is called chemo brain. Despite its name, it can happen to people having other types of cancer treatment.

People with dementia are more likely to have this side effect. Some of these problems are like the ones caused by dementia. For some people having treatment, dementia symptoms may get worse temporarily. For others, this change may be permanent. The doctor or nurse can give you more information and support before you and the person you care for decide if they will have treatment.

Poor appetite and eating problems

If the person you care for has symptoms of cancer or side effects from treatment, they may find it hard to eat.

Problems that can affect eating include:

- having a sore mouth
- difficulty swallowing
- diarrhoea
- constipation
- feeling sick.

If dementia is already affecting their appetite, this may be worse. Some people may struggle to eat enough. Others may eat more than usual, which can lead to weight gain.

If you think the person you care for is not eating well, ask their GP or specialist nurse to refer them to a dietitian. Dietitians can give advice about any changes you can help them make. If the person you care for is struggling to eat and losing weight, the dietitian may give them food supplements.

Eating a balanced diet and keeping to a healthy weight may help stop problems such as constipation and dehydration. These problems can make confusion worse for people with dementia.

Here are some healthy eating tips to help someone with cancer and dementia:

- Make sure the person you care for does not overeat.
- 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. This will help prevent constipation.
- Encourage them to drink plenty of fluids during the day. About 2 litres (3½ pints) can help prevent constipation and stop them from becoming dehydrated.
- If they find it hard to use cutlery, try foods they can pick up with their fingers.
- Help them look after their teeth with regular dental checks. If they have dentures, make sure they fit properly.

We have more information about diet in our booklets:

- **Eating problems and cancer**
- **The building-up diet**
- **Managing weight gain after cancer treatment**
- **Healthy eating and cancer.**

Dementia UK has a leaflet on helping someone with dementia look after their teeth and mouth (see page 87).

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 not drinking enough. They may also get constipated because:

- they are not eating enough
- they cannot move around enough
- they 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 laxatives, suppositories or enemas.

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

People often worry that cancer causes severe pain. But not everyone will have pain, even if the cancer is advanced. If the person you care for is in pain, it can usually be controlled with 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:

- become agitated or tearful
- 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.

Doctors and nurses can use a tool to assess if these behaviours are caused by pain or something else. The tool is a checklist of types of behaviour. It looks at how mild or severe the behaviour is. This can help hospital doctors or GPs decide whether to give someone painkillers.

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, they can be given painkiller patches that stick to the skin.

You can do some simple things to help with pain and discomfort in the person you care for. You could try:

- changing their position
- using heat pads, hot water bottles or ice packs
- asking if they would like a massage.

You could also offer them over-the-counter or prescribed painkillers regularly. You should only give these exactly as instructed on the packet.

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** (see page 82).

Sleep problems

Having both cancer and dementia may cause problems sleeping at night. Getting a good night's sleep can stop someone with dementia from feeling tired during the day. 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** (see page 82). We also have information about sleep problems and advice on how to get a good night's sleep at **macmillan.org.uk**

'Sundowning' is when a person's dementia symptoms get worse in the evening, around dusk. Dementia UK has more information explaining sundowning and how to cope with the effects (see page 87). You can download this information from **dementiauk.org/changes-in-behaviour**





PRACTICAL HELP AND SUPPORT

Organising help and services

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Organising help and services

If you need support and services to help you care for someone in their home, you can ask the GP and district nurses to make referrals.

If the person you care for is coming home from a stay in hospital, any help and services they need can be set up so that they start when the person gets home. The hospital staff usually does this, with the help of a social worker.

All hospitals have policies to make sure:

- a person is safely discharged
- the care they need at home has been organised.

Holistic needs assessment

The person you care for may have a holistic needs assessment before they come home. In the assessment, you will both be asked a lot of 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 nurse about this. More information can be found in our booklet **Holistic Needs Assessment: Planning your care and support** (see page 82).

Planning for hospital discharge

If there are lots of things to discuss before someone leaves a hospital or hospice (is discharged), hospital or hospice staff 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 (OT)
- a social worker.

If you are the main carer, you should be involved in any discharge planning. You should never be left to take the person home without the right help and support in place.

If you are not sure of the plans, talk to the nurses or ward manager. They can discuss the plans with you. They can also arrange for you to see the social worker to talk about any help you may need. This is called a carer's assessment (see page 48). If you are not happy with anything that has been arranged, let them know.

Tips for planning a hospital discharge

- If you find it difficult to discuss your needs with the hospital staff, try writing things down. You may also find it helpful to have someone else with you. As well as giving you support, they can remind you of anything you may have forgotten.
- If the situation changes, remember that plans can be changed. For example, when the person you care for first leaves hospital, you may not need any help looking after them. But if they begin to become more dependent, you may need help with their personal care. This could include washing, dressing and eating.
- 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 has been assessed as not being eligible 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. 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 (see page 75). 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 visit the [gov.uk](https://www.gov.uk) or [nhs.uk](https://www.nhs.uk) websites for more information.

Our booklet **Looking after someone with cancer** has more information about the carer's assessment (see page 82). You can also visit [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

Who can 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 looked after at home. They will assess the person you care for. They can refer them to other services, such as:

- district nurses
- community palliative care nurses
- social workers
- occupational therapists
- physiotherapists.

If needed, they can also arrange for them to go into a hospital, nursing home or hospice.

District nurses

District nurses work closely with GPs. If needed, they make regular visits to people at home. They provide any nursing care the person might need.

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
- expert guidance
- practical solutions to help face dementia with more confidence and less fear.

Most Admiral Nurses work in the community for the NHS, but some work in care homes, hospitals or hospices.

To find out if there is an Admiral Nurse in your local area:

- call Dementia UK's Admiral Nurse Dementia Helpline on **0800 888 6678**
- email **helpline@dementiauk.org**

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 will find their number in the phone book or 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 has its own eligibility criteria. So the services offered will vary from area to area.

The hospital social worker can give you information about social services and benefits 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 fares.

The social worker can also do an assessment of your needs as a carer. This is called a carer's assessment (see page 48).

Occupational therapists and physiotherapists

A physiotherapist or occupational therapist can help if the person you care for is unsteady on their feet or needs help moving around. You could ask their GP or specialist nurse for a referral.

Physiotherapists give help and advice on exercises and ways to keep the person as mobile as possible.

Occupational therapists can suggest and arrange minor changes to the home, such as handrails or stairlifts. They can also order wheelchairs or equipment to make bathing or showering easier.

Dietitians and speech and language therapists

Dietitians are qualified health 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 (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 if they can be referred.

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 type of help they give will vary depending on where the person you care for lives. It 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.

Home helps are available in some parts of the UK. They offer a variety of services, including cleaning, washing, cooking and shopping. The local social services department, social worker, community nurse or GP will know what is available in your area.

Our booklet **Looking after someone with cancer** has more detailed information about professionals and services that can help (see page 82).

Voluntary organisations and charities

Voluntary organisations and charities offer various kinds of help.

This may include:

- information
- loans of equipment
- grants
- transport.

Some organisations have volunteers who offer short periods of respite care to give you a break during the day. Others, including Marie Curie, provide befriending services for people who are on their own (see page 95). 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

58



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 of when 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 see the GP promptly.
- Help them keep up to date with hearing, eye and dental checks to find any problems early. You and the person you care for may also be able to have the annual flu jab.

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 tips on helping someone with cancer and dementia manage eating problems and their diet on pages 35 to 36.

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.

It may also reduce stress and help them sleep better.

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.

If they can manage short walks or gentle stretching exercises, you could help them do this. You could check if there are any exercise classes in the local area.

Age UK runs exercise classes in some areas of the UK (see page 91). They also have a leaflet called **Strength and balance exercises for healthy ageing** which you may find helpful.

We have more information in our booklet **Physical activity and cancer** which you may find useful (see page 82).

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 had. It is not advisable to drink alcohol with some medicines. Check with the GP or pharmacist if it is safe for the person you care for to have alcohol. People whose dementia is linked to drinking alcohol in the past should not drink alcohol.

Giving up 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. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

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
- they need to be careful to avoid infection
- they have side effects – so they can let their healthcare team know
- they need to take cancer medicines in addition to their usual everyday medicines.

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

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Being a carer

Looking after someone with cancer and dementia can be both rewarding and challenging. Depending on the stage of their illness, they may need lots of help with everyday activities.

This could include washing, dressing and cooking.

It can be hard to know if you are getting all the help that is available and if you are supporting the person you care for in the right way. This information explains some of the ways you can look after yourself while looking after someone with cancer and dementia. We have more information on health and social care teams that can help you. Visit macmillan.org.uk

Our booklet **Looking after someone with cancer** has practical information and advice that you may find useful (see page 82).

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 close family and friends. You may like to talk to someone else. Ask your GP to refer you to a counsellor or support group. If you need more support, you can call the Macmillan Support Line on **0808 808 00 00**. Or you can call Dementia UK's Admiral Nurse Dementia Helpline on **0800 888 6678**.

Looking after yourself

It is important to look after yourself while looking after the person you care for. Here are some ways you can do that.

Take breaks

Having some time for yourself can help you to relax and feel able to cope better. This can also help the person you are caring for.

You may be able to arrange for someone to help regularly. This gives you some time to yourself, even if it is only for a few hours each week.

Make time for you

When you get time off, try to relax or enjoy yourself by doing something different. You may feel tempted to spend time cleaning the house or doing the washing. But this is unlikely to help you feel better in the long term. Make sure you do something that you want to do and switch off for a while.

Eat well

Try to eat healthily. If you can, make time to prepare and sit down for a cooked meal every day. If you do not have time, perhaps you could ask a friend to help you.

Be active

Try to be active and get some fresh air every day. This could just mean a short walk. This will help keep you more mentally alert. It may also help you feel less tired and stressed.

Use relaxation techniques

Many people find relaxation techniques can help. You can use CDs or DVDs, which may be available to borrow from your local library or to buy. Or you can listen to a relaxation podcast.

Some people find having a massage relaxing. It can be a great way to switch off for a short time. Your local carers' centre or Macmillan Information Centre may offer free complementary therapies for carers (see page 83).

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 be thinking and worrying about the person you care for, which can keep you awake. Or they may be having a bad night, which can also keep you awake.

If you are having difficulty sleeping, there are things you can do that may help. For more information visit macmillan.org.uk

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 about what support is available locally. We also have information on support groups at community.macmillan.org.uk/cancer_experiences/carers-only-forum

Online support groups or chat rooms

On our Online Community, you can chat to other people looking after someone with cancer. You can stay anonymous and chat instantly to other people in a similar situation. You can find more information at community.macmillan.org.uk

Alzheimer's Society also has an online forum specifically for those caring for someone with cancer and dementia (see page 86).

Our cancer support specialists can help you find out what is available in your area. Call **0808 808 00 00** to speak to them.

You can get also information and advice from Carers UK or Carers Trust (see page 88).

Caring for someone with advanced cancer and dementia

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 nurse will make sure they have treatments to manage any symptoms they may have. 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

Hearing 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 of Counselling and Psychotherapy (see page 90). 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 **A guide for the end of life** that you may find useful (see page 82). It is meant for people in the final stages of life, and their carers.

There is still much to be done to ensure that the needs of patients with dementia and cancer are met. It is not enough only to know that a patient has dementia – there needs to be a clear plan in place as to what that means and what needs to be done differently because of it in terms of a person’s care.

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



PRACTICAL ISSUES

Working and caring

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Working and caring

If you are caring for someone, you may have to give up work or work part-time so you can be at home more. This may be a difficult time financially.

Finding a balance between work and caring can be difficult, but it is not impossible.

Our booklet **Working while caring for someone with cancer** and leaflet **Questions for carers to ask about work and cancer** may be useful (see page 82). They give helpful advice on:

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

We also have videos of carers talking about their experiences of working while caring. Visit [**macmillan.org.uk/work**](https://www.macmillan.org.uk/work)

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 give up work 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 call our welfare rights advisers on **0808 808 00 00** to find out more about which benefits you may be able to get.

Dementia UK's Admiral Nurses can also give financial advice to people affected by dementia. Call them on **0800 888 6678**.

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.

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.

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 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.

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 6 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 (see page 82).

Dementia UK has a leaflet called **Sources of support and advice** (see page 87). It explains the tax exemptions and financial sources of support available to people looking after someone with dementia.

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 (see page 85).

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 financial guides who can help you understand your insurance policies. Call **0808 808 00 00** to speak to one.

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 page 93).

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. You can find more information in our booklet **Help with the cost of cancer** (see page 82). Or you can call our financial guides for more guidance and support. Call us on **0808 808 00 00**.

We have a benefits calculator to help you find out what you might be able to get. We also have a budget planner to help you work out a weekly or monthly budget. For more information visit **macmillan.org.uk**

I am extremely grateful that there are services to help and support. I am aware that in many places and countries there is not the support in cancer, dementia and mental health that we have.

Penny, Online Community



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About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we 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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would 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 is 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.

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

Whether you are 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](https://www.macmillan.org.uk/work)**

Work support

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

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 Society (England, Wales and Northern Ireland)

Dementia Connect Helpline **0300 150 3456**

www.alzheimers.org.uk

Provides a free helpline and email advice, and written information about dementia, treatment and living with dementia.

Use the online community to share experiences with other people affected by dementia.

Alzheimer's Scotland

Helpline **0808 808 3000** (Daily, 24 hours)

www.alzscot.org.uk

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

Dementia UK

Helpline **0800 888 6678**

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

Email **helpline@dementiauk.org**

www.dementiauk.org/get-support

Provides practical and emotional information and support to people with dementia and their carers. It has a free helpline and, in some parts of the UK, Admiral Nurses. Admiral Nurses provide the specialist dementia support that families need. They work alongside people with dementia and their families, giving them the one-to-one support, expert guidance and practical solutions they need to face dementia with more confidence and less fear

Aids for memory problems

AT Dementia

Tel **0115 748 4220**

Email **info@trentdsdc.org.uk**

www.atdementia.org.uk

An online information resource on assistive technologies (including telecare) for people with dementia. Includes a self-help guide offering advice about assistive technologies – visit **asksara.dlf.org.uk**

Live Better with Dementia

Email **theteam@livebetterwith.com**

dementia.livebetterwith.com

Specialist retailer of dementia and memory loss products, living aids and activities.

Support for carers

Carers Direct

Helpline **0203 904 4520**

www.carersdirect.org

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

Carers Trust

Tel (England) **0300 772 9600**

(Scotland) **0300 772 7701**

(Wales) **0300 772 9702**

(Northern Ireland) **0782 693 0508**

Email **info@carers.org**

www.carers.org

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

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**

(Mon to Fri, 9am to 6pm)

Helpline (Northern Ireland) **028 9043 9843**

Email **advice@carersuk.org**

www.carersuk.org

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

Care regulators

The Care Quality Commission (England)

Tel 0300 0616 161

www.cqc.org.uk

Monitors, inspects and regulates services to make sure they meet fundamental standards of quality and safety.

The Care Inspectorate (Scotland)

Tel 0345 600 9527

Email enquiries@careinspectorate.com

www.careinspectorate.com

Works to make sure that everyone gets safe, high-quality care that meets their needs.

The Care and Social Services Inspectorate (Wales)

Tel 0300 7900 126

(Mon to Thu 9am to 5pm, and Fri 9am to 4pm)

Email ciw@gov.wales

www.careinspectorate.wales

Regulates and inspects, to improve adult care, childcare and social services for people in Wales.

The Regulation and Quality Improvement Authority (Northern Ireland)

Tel 0289 536 1111

Email info@rqia.org

www.rqia.org.uk

Registers and inspects a wide range of health and social services.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **01455 883 300**

Email **bacp@bacp.co.uk**

Promotes awareness of counselling and signposts people to appropriate services across the UK.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**

Email **info@ukcp.org.uk**

www.psychotherapy.org.uk

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

Emotional and mental health support

Mind

Helpline **0300 123 3393**

Email **info@mind.org.uk**

www.mind.org.uk

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

Samaritans

Helpline **116 123**

Email **jo@samaritans.org**

www.samaritans.org

Samaritans branches are located across England, Ireland, Scotland and Wales. 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 **0344 800 0550** (Mon to Fri, 9am to 6pm)

Email **info@samh.org.uk**

www.samh.org.uk

Has support services across Scotland for mental health social care support, homelessness, addictions and employment.

Support for older people

Age UK

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

www.ageuk.org.uk

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

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**

Textphone **020 7562 2050**

Email **contactus@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.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)

Email **info@dlf.org.uk**

www.livingmadeeasy.org.uk

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

Disability Rights UK

Tel **0330 995 0400** (not an advice line)

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.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**

(Mon to Fri, 9am to 9pm)

Email **helpline@lgbt.foundation**

www.lgbt.foundation

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

Financial and legal advice and information

Advice NI

Helpline **0800 915 4604**

Email **advice@adviceni.net**

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

Benefit Enquiry Line Northern Ireland

Tel **0800 232 1271**

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

Textphone **0289 031 1092**

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

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

Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317** (Mon to Fri, 8am to 6pm)

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 in the phone book or 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

Department for Work and Pensions (DWP)

Textphone **0800 121 4493** (Mon to Fri, 9am to 5pm)

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.

Personal Independence Payment (PIP)

Tel **0800 121 4433**

The Law Society

Tel **020 7242 1222**

www.lawsociety.org.uk

Represents solicitors in England and Wales, and can provide details of local solicitors.

Law Society of Scotland

Tel **0131 226 7411**

Email **lawscot@lawscot.org.uk**

www.lawscot.org.uk

Law Society of Northern Ireland

Tel **0289 023 1614**

www.lawsoc-ni.org

Money Advice Scotland

Tel **0141 572 0237**

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

www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

Social Care Institute for Excellence (SCIE)

Tel **020 7766 7400**

Email **info@scie.org.uk**

www.scie.org.uk

Gives information about independent advocates and other practical advice.

Advanced cancer and end-of-life care

Compassion in Dying

Tel **0800 999 2434**

Email **info@compassionindying.org.uk**

www.compassionindying.org.uk

Supports people at end of life. Gives information about how to talk about it, plan for it, and record your wishes.

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.

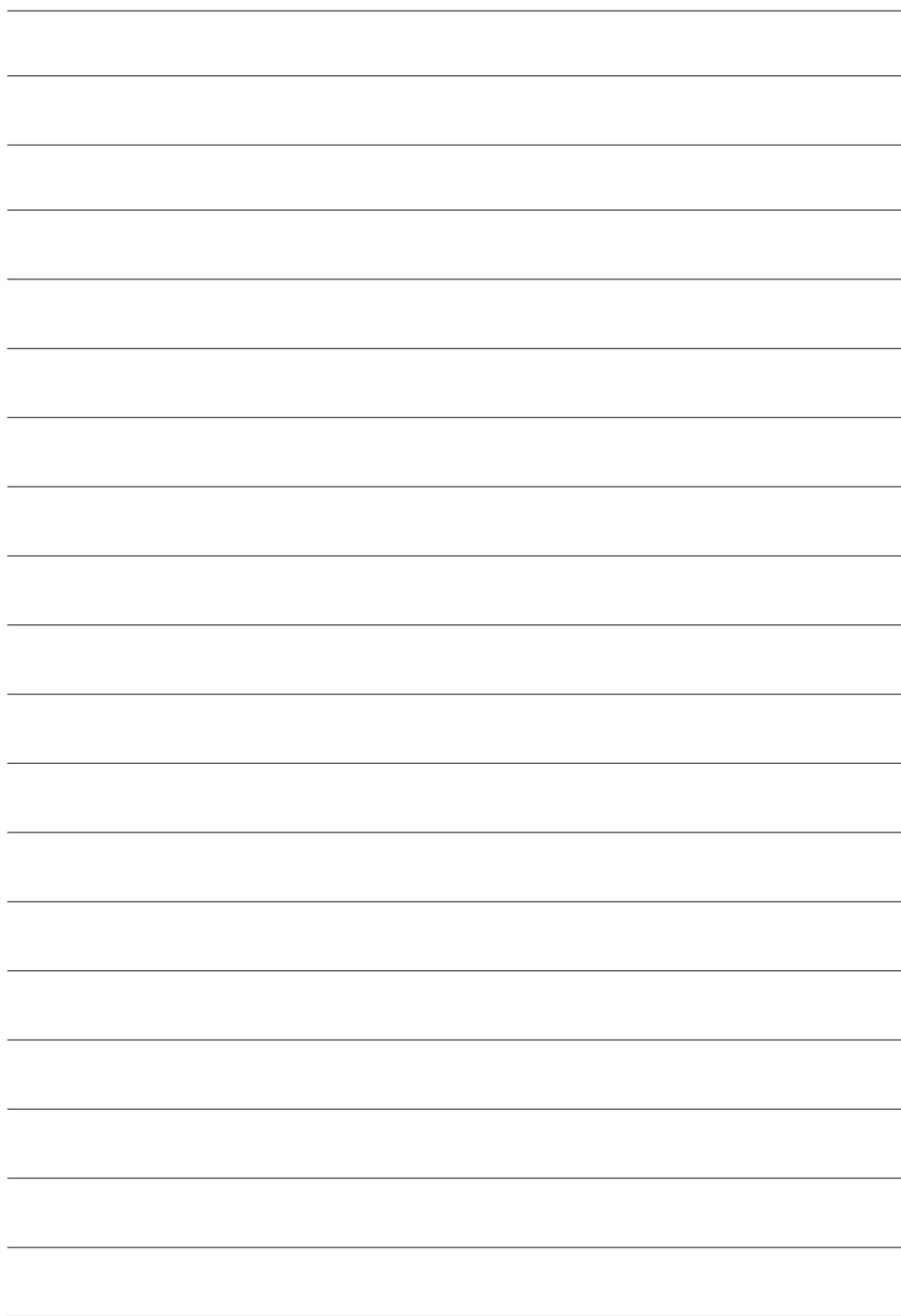
Marie Curie

Helpline **0800 090 2309**

(Mon to Fri, 8am to 6pm, and 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.



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 our Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Laura Ashley, Reader in Health Psychology; Dr Rachael Ayres, Consultant in Elderly Medicine; Dr Laura Brown, Consultant in Elderly Medicine; Lorraine Burgess, Macmillan Cancer and Dementia Nurse Consultant; Dr Karen Harrison Denning, Head of Research and Publication, Dementia UK; Joanna James, Lead Nurse for Dementia; Dr Hannah Johnson, Consultant in Elderly Medicine; Dr Robert Stevenson, Consultant Clinical Oncologist; and Professor Claire Surr, Centre for Dementia Research, Leeds Beckett University.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in our information about caring for someone with dementia and cancer.

If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Alzheimer's Society. Dementia 2015: Aiming higher to transform lives. 2015.

Gosney et al. Dementia and Cancer: A review of current literature and practices. 2013.

The Dementia Engagement and Empowerment Project (DEEP) Guide: Writing dementia-friendly information. 2013.

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

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

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Mr/Mrs/Miss/Other

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Surname

Address

Postcode

Phone

Email

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OR debit my:
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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



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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 cancer and dementia. It is for anyone who looks after a friend or family member who has both cancer and dementia.

The booklet has practical advice about ways to look after yourself when you care for someone who has cancer and dementia.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

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

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

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



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