

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.

It includes tips on how to get support and look after yourself.

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

If you have more questions about cancer or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit [macmillan.org.uk](http://macmillan.org.uk)



**DementiaUK**

Helping families face dementia

If you have questions about dementia, call our Admiral Nurse Dementia Helpline on **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org), Monday to Friday, 9am to 9pm, and Saturday to Sunday, 9am to 5pm, or visit [dementiauk.org](http://dementiauk.org)

© Macmillan Cancer Support, September 2017. 1<sup>st</sup> edition. MAC16831. Next planned review 2020. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.

 Health & care  
information  
you can trust

The Information Standard  Certified Member

What's this logo? Visit [macmillan.org.uk/ourinformation](http://macmillan.org.uk/ourinformation)



A guide for carers

# CANCER AND DEMENTIA

## A GUIDE FOR CARERS



Together with Macmillan



**DementiaUK**  
Helping families face dementia

# About this booklet

This booklet is about cancer and dementia. It is for anyone who cares for someone with both cancer and dementia. There is also information for family members and friends.

Living with 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** that 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.uk** Read more about how Dementia UK can help you on page 80.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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

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

## How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list opposite to help you.

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

We have included quotes from people who have had cancer and dementia and their carers, which you may find helpful. Some are from members of the Great Camden Minds Dementia Engagement and Empowerment Project (DEEP) group. Others are from our Online Community – visit **community.macmillan.org.uk** There are also quotes from healthcare professionals. Some names have been changed.

To share your experiences, visit **macmillan.org.uk/shareyourstory**

# Contents

Understanding cancer and dementia	5
Dementia and treatment for cancer	13
Planning for the future	21
Symptoms and side effects	31
Practical help and support	39
Living with cancer and dementia	49
Caring for someone with cancer and dementia	55
Practical issues	65
Further information	73



# UNDERSTANDING CANCER AND DEMENTIA

---

About cancer and dementia	6
What is cancer?	7
What is dementia?	9

## About cancer and dementia

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

Each year, about 352,000 people in the UK are diagnosed with cancer and about 850,000 people are living with dementia. Many people with dementia also have several 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.

*'Dealing with Dad's dementia alongside his cancer diagnosis and treatment is, at times, challenging on my part.'*

**Mary, who cares for her father**

## What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues in our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair.

Cells receive signals from the body telling them when to divide and grow, and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and dies.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells.

These may form a lump (tumour), which may be cancer. Sometimes blood cancers develop when blood cells become abnormal.

Doctors may remove a small sample of tissue or cells. This is called a biopsy. The doctor then examines the sample under a microscope to look for cancer cells.

## Treatments for cancer

The main treatments for cancer are surgery, radiotherapy, chemotherapy, hormone therapy and targeted therapies.

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.

The doctor will consider all these things when planning treatment. They can affect how well certain cancer treatments work or whether someone is well enough to have them.

## What is dementia?

Dementia is a word used to describe a set of symptoms. There are several types of dementia, so each person affected may have different symptoms.

Dementia is caused by damage to the brain. This damage is mainly from Alzheimer's disease or strokes (vascular dementia). Symptoms will depend on what has caused the damage and which part of the brain is affected.

Symptoms can include:

- problems thinking clearly
- finding it hard to solve simple problems
- not remembering or using the right words
- being confused or disoriented
- changes to behaviour or personality.

Dementia is usually thought of in three different stages – early, middle and late. These stages are a guide to how dementia might develop over time. But dementia is different for each person and the stage will depend on different factors, including:

- the type of dementia
- the person's general health
- the support available
- whether the person is having treatment for dementia.

Some people may not notice symptoms at first. Or symptoms may come and go, while others get worse over time (progressive). As the dementia moves into a later stage, someone with dementia may need help with everyday activities.

Sometimes the stages of dementia overlap. This may mean they need help with one type of task or activity, but can manage others on their own.

Some types of behaviour can be challenging and distressing.

## Treatments for dementia

Currently, there are no treatments to prevent or cure dementia. But researchers are looking at medical treatments and vaccines.

Some treatments may help to improve the symptoms, but these are mostly only for people with Alzheimer's disease. The treatments can sometimes slow dementia for a while.

Drug treatments for dementia have some side effects that mean they are not suitable for everyone. Doctors and nurses who specialise in dementia can tell you more about which treatments may be suitable for the person you care for.

There are two main types of treatment for dementia:

- **Non-drug treatments** – these may include talking therapies, counselling and support at home.
- **Drug treatments** – these include drugs that can help for a while with memory problems, and drugs that can help with hallucinations or treat depression and anxiety.

People who have dementia caused by strokes may be given drug treatments to treat the cause of the strokes. This might include drugs for high blood pressure, heart problems or high cholesterol. They may also be given advice about lifestyle changes that may help, such as stopping smoking.

Talk to the dementia doctor or nurse to find out more about treatment for dementia and what might help.



# DEMENTIA AND TREATMENT FOR CANCER

---

Treating cancer in someone with dementia	14
Appointments and hospital visits	18

## Treating cancer in someone with dementia

The cancer treatment offered to the person you are caring for will depend on their individual situation, but also on the stage of the dementia (see page 9). Doctors and nurses who specialise in cancer can talk to you about which cancer treatments might help in their situation.

### Benefits and disadvantages of treatment

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

The person you care for is likely to have side effects from cancer treatments. These are usually temporary and can be controlled with medicines.

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

Some people may not be well enough for standard treatment. This may be because of other health problems. Other people may choose not to have the standard treatment. Instead, they may have other treatments that give a lower dose of treatment or fewer treatments. They will usually spend less time in hospital and have fewer side effects. These types of treatments are given to control the cancer but they won't get rid of it completely.

Sometimes the treatment stops working. If this happens, the person can still be given supportive or palliative treatment to help control symptoms (see pages 32 to 36). If someone is having problems with symptoms or side effects, they can have supportive treatments for any stage of cancer.

Talk to the person you care for about whether they would like to have treatment and what they might prefer. You could 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.

### 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, they 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.

## 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
- be able to make an informed decision.

A person with dementia must be able to remember the information for long enough to make an informed decision.

If someone has dementia, their capacity can be affected. The specialist doctor looking after them may need to check whether they can make an informed decision about treatment.

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 partners, family or friends.

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 that they would or would not want to have. This is known as making Advance Decisions – see page 24 for more information.

If you are the carer of 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 will be able to give you some advice about the best way to do this.

Alzheimer's Society has a fact sheet called **Making decisions and managing difficult situations** that you may find useful. You can download it at [alzheimers.org.uk](http://alzheimers.org.uk)

'The hospitals are very respectful and tactful in how they are with Dad. Even though they know he will have no recollection of what was said, they still have the utmost respect and keep his dignity by involving him in every way. Which is a great thing and makes me happy because, despite the dementia, he still feels like he is important and has a say.'

**Mary**

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

You can also ask the health professional to communicate in ways that are helpful. It might help if the health professional does the following:

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

If the person you are caring for is admitted to hospital, it is important that everyone involved in their care knows about their needs. It also helps if people know what the current care plan is or if anything has changed.

Alzheimer's Society have an information form called **This is me**. It can be filled out by people with dementia and their carers. It is helpful for the person with dementia if they are in an unfamiliar place, such as hospital or respite care, especially if they are having problems communicating. You can download or order the form at [alzheimers.org.uk/thisisme](https://www.alzheimers.org.uk/thisisme) or by calling **0300 222 11 22**.

'Having consultants and doctors wearing ID badges makes such a difference. Just because they introduce themselves at the start doesn't mean you will remember it.'

**George, a member of the Great Camden Minds DEEP group**



# PLANNING FOR THE FUTURE

---

<b>Making choices</b>	<b>22</b>
<b>Wishes for care and Advance Statements</b>	<b>23</b>
<b>Advance Decisions to Refuse Treatment and Advance Directives</b>	<b>24</b>
<b>Lasting Power of Attorney</b>	<b>25</b>
<b>Care options</b>	<b>27</b>

## Making choices

If someone has dementia, it is likely that their ability to make decisions (mental capacity – see page 16) will be affected in the future. There may come a time when they will not be able to make certain decisions or communicate easily. If they think ahead about their future care and treatment, it can help you and any other carers, such as health professionals.

There are different ways the person you care for can plan ahead. This is sometimes known as advance care planning and includes:

- their wishes and preferences for care
- Advance Statements
- Advance Decisions (or Directive) to Refuse Treatment
- Lasting Power of Attorney.

## Wishes for care and Advance Statements

The person you care for can talk to you or someone else they trust about how they would like to be cared for. They can also write down wishes and preferences for family or health and social care professionals. These are called Advance Statements.

Advance Statements of wishes are not legally binding. But they must be taken into consideration when healthcare professionals make decisions about the person's care.

There are different documents that can be used to record wishes and preferences. You can ask the person's doctor or nurse which documents are used in their area.

## Advance Decisions to Refuse Treatment and Advance Directives

An Advance Decision to Refuse Treatment or Advance Directive is sometimes known as an Advance Decision. It is a decision about treatments the person you are caring for doesn't want to have. For example, they may decide that if their breathing stops, they don't want people to try to bring them back to life (resuscitate them). Or, that if they are very ill and have an infection, they don't want to be given antibiotics.

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

## Lasting Power of Attorney

The person you care for can give one or more other people the legal power to manage their affairs. This is called Power of Attorney. These decisions may be about property or finances, or health and welfare.

Although someone can create their own Power of Attorney (PoA), it can help to speak to a solicitor. They will make sure that your PoA meets all the requirements of the law. If you don't have a solicitor, you can find one by contacting The Law Society (see page 86).

Power of Attorney can vary depending on what part of the UK you live in.

You can read more information in our booklets **Your life and your choices: plan ahead**. There is one version for England and Wales, one for Scotland, and one for Northern Ireland. See page 27 for details about how to order this information.



## Care options

It can be helpful for the person you care for to think ahead and make some decisions about where they will 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 in
- their medical condition.

Most people prefer to stay at home, as long as 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 during the day if you have to work. Hospices and residential homes may also offer short stays for a few days or weeks. This might be to have 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 for them to go into care for a short while. This might be in a:

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

## Care in residential homes or nursing homes

Residential and nursing homes offer short-term or long-term accommodation and care. Residential care homes or care homes with nursing provide different levels of care. A social worker or member of the healthcare team can explain the difference.

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 care home arrangements and how to arrange this type of care. Organising care homes can take some 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 (see page 82 for their contact details).

Before choosing a care home or agency, you may want to check its standard of care with one of these organisations. You can also ask your healthcare worker or social worker to give you this information.

## Hospice care

If the person you care for becomes more unwell, 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 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 and then go back home.

Hospices are generally smaller and quieter than hospitals and work at a much gentler pace. Many have sitting rooms and space for family to stay overnight. Sometimes there is a waiting list to go into a hospice but this is usually short. If you are not sure about the idea of hospice care, you can ask to visit before making a decision.



# SYMPTOMS AND SIDE EFFECTS

---

Managing symptoms and side effects

32

## Managing symptoms and side effects

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

You can read more about the most common ones in our booklets **Managing the symptoms of cancer** and **Side effects of cancer treatment**. See page 74 for information on how to order copies of these booklets.

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. It can help to look for signs in their body language or facial expressions.

Some symptoms or side effects of cancer may be similar to ones caused by dementia. If the person you care for has symptoms that 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 similar to ones caused by dementia and you may worry that the dementia is getting worse. But the symptoms of chemo brain are usually temporary and should improve with time.

The doctor or nurse can give you more information and support.

We have more information about chemo brain we can send you – see page 74 for contact details.

### Poor appetite and eating problems

If the person you care for has symptoms or side effects from cancer treatment, they may find it hard to eat. Problems such as having a sore mouth, difficulty swallowing, diarrhoea, constipation or feeling sick can affect how well they eat. 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 they are struggling to eat and are losing weight, the dietitian may give them food supplements.

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

Here are some healthy eating tips for people with cancer and dementia:

- They should try not to over eat.
- They should eat less saturated fat and sugar.
- They should eat plenty of fruit, vegetables and high-fibre foods. This will help keep their bowels regular.
- You could encourage them to drink about 2 litres (3 and a half pints) of fluids a day. This will also help keep their bowels regular. It will also stop them from becoming dehydrated.
- If they find it hard to use cutlery, try foods that they can pick up with their fingers.
- Help them look after their teeth with regular dental checks and make sure dentures fit properly.

Our booklet **Eating problems and cancer** has more information on ways to get help. Our booklet **The building-up diet** has practical tips for getting more calories in your diet. Our booklet **Healthy eating and cancer** includes a healthy eating guide. There is information on page 74 about how to order copies.

## Constipation

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

The main reason people with cancer and dementia get constipated is not drinking enough. Some people get constipated because they aren't eating enough, Others get constipated because they can't move around much. Painkillers can also 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 the GP, district nurse or specialist nurse. They may recommend laxatives, suppositories or enemas.

It can help to keep a note of their bowel movements. That way you can prevent or treat constipation before it becomes severe or affects their confusion.

## Pain

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

Some people with dementia may not be able to tell their carers that they are in pain. Look for signs of pain in their behaviour, such as:

- becoming agitated, tearful or shouting out
- holding the part of their body that is sore
- changes in facial expression or clenching teeth
- being pale or sweaty
- refusing help or care.

Doctors and nurses can use a tool to assess whether these behaviours may be caused by pain or something else. The tool is a check list of types of behaviours. It looks at how mild or severe the behaviour is. This can help hospital doctors or GPs to make decisions about whether to give the person painkillers.

Painkillers are usually tablets or capsules. The person you care may have problems swallowing medicines or remembering to take them. In this situation, they can be given painkiller patches that stick to the skin.

You can do some simple things to help with pain and discomfort. You could try:

- changing their position
- using heat pads, hot water bottles or ice packs
- giving them a massage.

Sometimes the person may need specialist help to assess their pain and symptoms (see page 35). 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 (see page 29). Once their symptoms are controlled, they will be able to go home again.

Our booklet **Controlling cancer pain** has more information about pain and ways to manage it – see page 74.

## 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 can be different reasons why someone is not 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 are able to 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 symptoms or side effects of cancer treatment. You may also be able to get equipment that could make them more comfortable, such as a pressure-relieving mattress.

Some people find that anxiety, worry and emotional distress is 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.

Our booklet **Talking with someone who has cancer** has helpful information about starting conversations and listening. We also have information about sleep problems and advice on how to get a good night's sleep – see page 74.



# PRACTICAL HELP AND SUPPORT

---

Organising help and services 40

Who can help? 43

## Organising help and services

If the person you care for is coming home from a stay in hospital, any help and services needed can be set up to start when they get home. This is usually done by the hospital staff, with a social worker. See pages 43 to 47 for more information about the professionals who can help.

All hospitals and organisations 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 are caring for may have a holistic needs assessment before they come home. In the assessment, you will both be asked lots of questions about how you are feeling and what help you need. This is to make sure you get the right support. Everyone involved in the person's care should have a copy of this, including their GP. You can ask the nurse about this.

### Planning for hospital discharge

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

- the person 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 aren't sure of the plans, talk to the nurses or ward manager. They can discuss it 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 carers assessment (see page 42). 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 staff, try writing them down. You may 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 first goes home you may not need any help looking after them. But if they begin to become more dependant, you may need help with their personal care. This could include washing, dressing and eating.
- The person you are caring 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 isn't clear, ask for more details. You have the right to ask any questions you want.
- When the person you are caring for is discharged, make sure they have any medicine they need. You will need enough to last until a new prescription can be arranged from 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 is an opportunity to talk about any help you need.

Even if the person you are caring for has been assessed as not being eligible for support, you can ask for this assessment. It is important to keep healthy and 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 from your local authority. This means that you are given money to organise care services yourself, rather than the local social services organising and paying for them directly. You can ask your local council for more information about direct payments. Or you can visit [gov.uk](https://www.gov.uk) or the NHS Choices website at [nhs.uk](https://www.nhs.uk)

Our booklet **Looking after someone with cancer** has more information about the carer's assessment – see page 74. Or you can visit [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

## Who can help?

You don't 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 a number of 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 then refer them to other services, such as nurses, social work and occupational and physiotherapists. If needed, they can also arrange for them to go into hospital, nursing home or hospice.

### District nurses

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

## Specialist nurses

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

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

- assess needs
- give advice
- support people to understand their treatment options.

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

## Admiral Nurses

Admiral Nurses are specialist dementia nurses. They give expert practical, clinical and emotional support to families living with dementia to help them cope. They are registered nurses who have had significant experience of working with people with dementia before becoming an Admiral Nurse.

Most Admiral Nurses work for the NHS in communities. They aim to help people with dementia stay at home for longer. They also work in other settings, including care homes, hospitals and hospices.

To find out whether there is an Admiral Nurse in the local area:

- call Admiral Nursing Dementia Helpline on **0800 888 6678**
- email **direct@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 they don't already have a social worker, the GP or a nurse care can arrange a referral. Or you could contact the local social services department. You will find their number in the phone book under the name of your local authority, council or your health and social care trust.

The social worker will visit and do a community care assessment or needs assessment. Each local authority has its own eligibility criteria, so the services that are provided 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. This might include meals on wheels, a home helper or hospital fares.

The social worker can also do an assessment of your needs as a carer. This is called a carer's assessment. There is more information about this on pages 42.

## Occupational therapists and physiotherapists

If the person you care for is unsteady on their feet and needs help moving around, you could ask their GP or specialist nurse to refer them to a physiotherapist or occupational therapist.

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 their home, such as handrails or stairlifts. They can also help by ordering a wheelchairs or equipment to make bathing or showering easier.

## 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 the area, but 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 the area.

Our booklet **Looking after someone with cancer** has more detailed information on professionals and services that can help – see page 74.

## Voluntary organisations and charities

Voluntary organisations and charities offer various kinds of help. This may include giving information, loans of equipment, grants and transport.

Some organisations have volunteers who can provide 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. 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 access these health and social care professionals and voluntary organisations. They will also be able to tell you about the specific types of help and support available in the area.



# LIVING WITH CANCER AND DEMENTIA

---

Looking after everyday health

50

## 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 time and day 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 identify any problems early. You and the person you care for may also be able to have the annual flu jab.

'Being her daughter, I could be a little more insistent with things like medication. I just kept on saying, "Mum, you really have to. They are doing you good."'

**Georgina, a Healthtalk user**

## Eating well and keeping to a healthy weight

It is common for someone with cancer and dementia to have eating problems or struggle to keep to a healthy weight. See pages 33 to 34 for more information on what you can do.

## Keeping active

Being physically active can be good for the person you care for. It can help improve symptoms such as tiredness, poor appetite and constipation. Activity may also reduce stress and help them sleep better.

You could encourage them to start slowly and gradually build up the amount they do. To begin with, try to reduce the amount of time they spend sitting or lying down. Just moving around the house and doing simple day to day things will help.

If they can manage short walks or gentle stretching exercises, you could help them do this. Ask their GP or nurse if there are any exercise classes in the local area. Also ask if there are any physical activities that they should avoid.

Our booklet **Physical activity and cancer treatment** has more information – see page 74. AGE UK has a leaflet called **Strength and balance exercises for healthy ageing**. See page 84 for contact details.

## Alcohol and tobacco

People with dementia can become more confused after drinking alcohol. It is important that they limit how much they drink. They may need help remembering how much they have had. It's 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.

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. Our booklet **Giving up smoking** has more information and tips to help people quit – see page 74.

## Memory problems

Memory problems caused by dementia can be different for each person. They may include things like forgetting dates, appointments or names or getting lost in familiar places. Some people may continually lose everyday objects, such as keys or mobile phones, around the house.

Memory problems can be worrying and frustrating. But there are things you can do to help the person you care for:

- keep to routines and help them to only do one thing at a time
- get them to make lists and tick off completed tasks
- encourage them to complete everyday tasks in a calm, quiet environment with no distractions
- break information into small chunks to make it easier to remember
- if it helps, write the information down for them.

There is lots of information online about coping with memory loss. You can also order free booklets and leaflets, as well as CDs. For details of where you can get these, see the dementia organisations on page 80.

Alzheimer's Society has a book called **The memory handbook: A practical guide to living with memory problems** that you can download or order – see page 80.

## Assistive technology for memory problems

Assistive technology can help the person you care for to stay independent and improve safety in their home. These may be aids such as:

- clocks, calendars or phones that have numbers set into them
- safety devices to switch off gas supplies or taps if they are left on.

The details for organisations where you can get assistive technology are on page 81.

'Making lists and having a routine can really help.'

**Margaret, a member of the Great Camden Minds DEEP group**



# CARING FOR SOMEONE WITH CANCER AND DEMENTIA

---

Being a carer	56
Your feelings	57
Looking after yourself	58
Support from other carers	60
Caring for someone with advanced cancer and dementia	62

## 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 meal preparation.

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 section explains some of the ways you can look after yourself, as well as supporting someone with cancer and dementia. For information on health and social care teams that can help, see pages 43 to 47.

Our booklet **Looking after someone with cancer** has practical information and advice that you may find useful – see page 74.

## Your feelings

Finding out you that 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 our support line or Dementia UK's dementia helpline for free and talk to a specialist.

You could also find online communities helpful. These are online groups where other carers share their feelings and experiences. There are a few online communities where you can talk to other people going through the same thing, such as:

- our Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)
- Alzheimer's Society's Talking Point forum at [forum.alzheimers.org.uk/forum.php](https://forum.alzheimers.org.uk/forum.php)

Our booklet **Coping when someone close to you has cancer** has more information on coping with emotions – see page 74.

## Looking after yourself

It is important to look after yourself as well as 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 help the person you are caring for too.

You may be able to arrange for someone to help regularly (see page 46). 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, it is important to try to relax or enjoy yourself 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. The main thing is to 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 don't 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, DVDs or podcasts which may be available to buy at your local library. You may also find it helpful to listen to our CD **Relax and breathe** – see page 74.

Some people find having a massage very relaxing. It can be a great way for them to switch off for a short time. Your local carers' centre or Macmillan information centre may offer free complementary 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 be thinking and worrying about them, which can keep you awake. Or the person you are caring for 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. We have more information about difficulty sleeping – see page 74.

## 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. These include:

### Support groups led by carers

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

### Online support groups or chat rooms

You can stay anonymous and chat instantly to other people in a similar situation. On our Online Community you can chat to other people looking after someone with cancer. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

Our cancer support specialists can help you find out what is available in your area. Call **0800 808 00 00** to speak with them.

You can get confidential information and advice from Carers UK by calling **0808 808 7777**. The Carers Trust also provides support and advice across the UK – see page 81.



# 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. In this case, 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 be under the care of a palliative care team when they are first 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 team

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. Or you can call one of the support organisations listed on page 87. They will be able to talk things through with you.

Our booklet **End of life: a guide** has more information about coping at the end of life. It is aimed at people in the final stages of life and their carers. See page 74 for details on how to order a free copy.



# PRACTICAL ISSUES

---

Working and caring 66

Financial help and benefits 67

## Working and caring

This may be a difficult time financially. You may have given up work or work part-time so you can be at home.

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. They give helpful advice on flexible working, getting support at work and talking about cancer in the workplace – see page 74.

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 (see page 42). 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 fall.

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

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

### Carer's Allowance

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

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

### 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:

- Universal Credit, if either of you have a low income or are looking for work.
- Employment and Support Allowance for the person you care for, if they are unable to work because of illness.
- Personal Independence Payment for the person you care for if they are aged 16 to 64, or Attendance Allowance if they are aged 65 or above. They may be able to claim if they have problems looking after themselves or moving around. People who are not expected to live longer than six months can make a claim under the special rules claim for these disability benefits. This means they will receive payments sooner.

You may also be able to get help with travel costs and may 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 74 for details about ordering a free copy.

## Grants

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

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

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

## Insurance

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

Macmillan has financial guides who can help you understand your insurance policies. Call **0808 808 00 00** to speak with 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 pages 85 to 86).

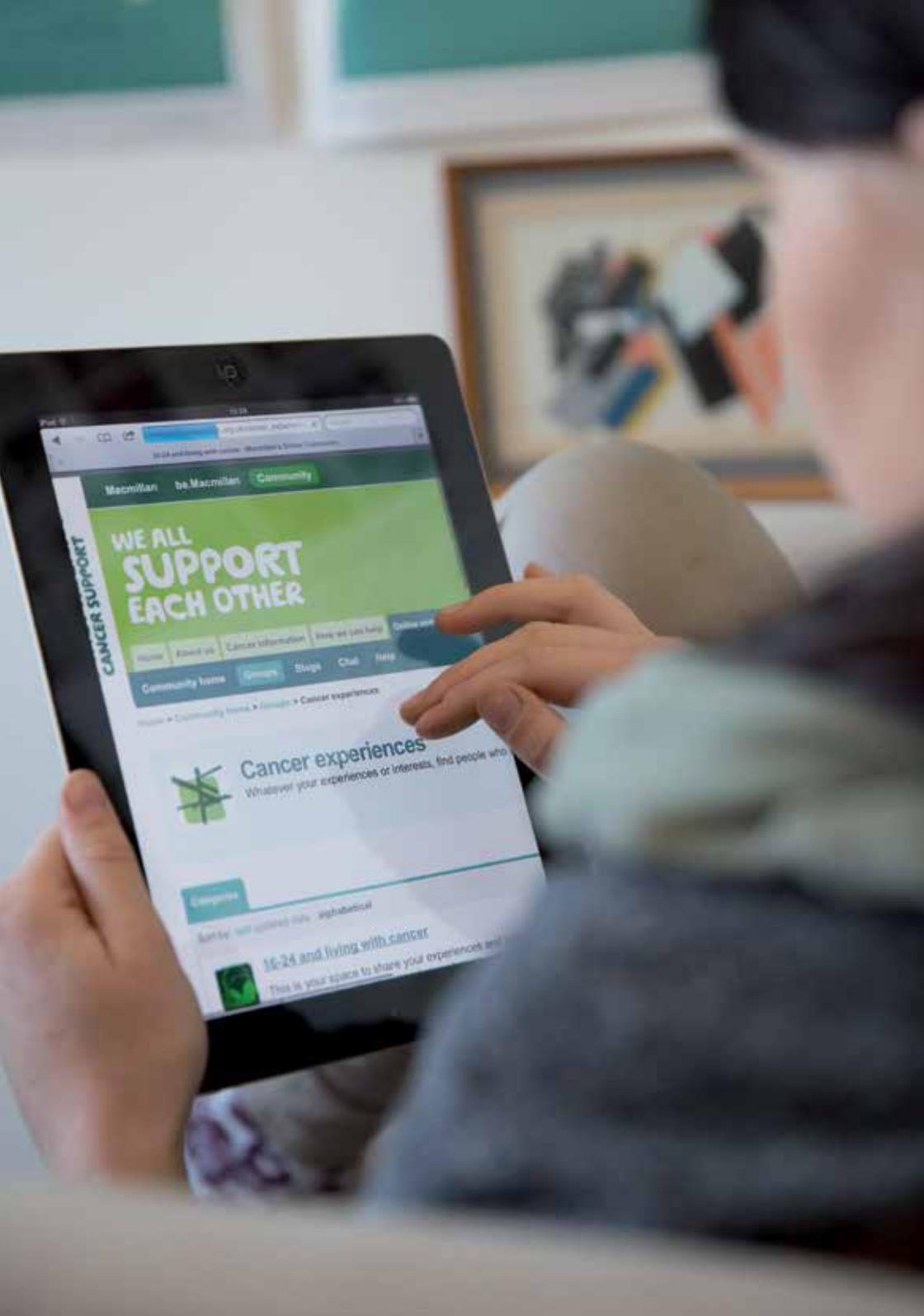
If you are having difficulty paying your mortgage, contact your mortgage lender as soon as possible and explain what has happened. They may agree to suspend payments for a while to give you time to sort your finances out, or suggest that you pay only the interest on the loan for a while. Another solution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

## More information

We have more information about all of these benefits and ways to get financial support. You can order our booklet **Help with the cost of cancer** or call our financial guides for more guidance and support (see page 74).

You can also find more information on our website. We have a benefits calculator to help you find out what you might be entitled to and a budget planner to help you work out a weekly or monthly budget. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)





# FURTHER INFORMATION

---

About our information	74
Other ways we can help you	77
Other useful organisations	80
Your notes and questions	88

## About our information

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

### Order what you need

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

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

### Online information

All of our information is also available at [macmillan.org.uk/information-and-support](https://www.macmillan.org.uk/information-and-support). There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

### Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats). If you'd like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

### Help us improve our information

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

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

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk). You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



## Other ways we can help you

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

### Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

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

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

### Information centres

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

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

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



## Talk to others

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

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand.

Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

## Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things.

You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](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're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

### Macmillan's My Organiser mobile app

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

## Other useful organisations

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

### Support with dementia

#### Dementia UK

**Helpline** 0800 888 6678

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

**Email** [info@dementiauk.org.uk](mailto:info@dementiauk.org.uk)

**www.**

**[dementiauk.org/get-support](http://dementiauk.org/get-support)**

Provides practical and emotional information and support to people with dementia and their carers through a free helpline and, in some parts of the UK, Admiral nurses. Admiral nurses are specialist nurses who give advice, practical and emotional support to carers as well as the person with dementia.

#### Alzheimer's Scotland

**Helpline** 0808 808 3000

(Daily, 24 hours)

**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)

**Helpline** 0300 222 11 22

(Mon to Fri, 9am to 8pm,  
Sat and Sun, 10am to 4pm)

**www.alzheimers.org.uk**

Provides free helpline and email advice and written information about dementia, treatment and living with dementia. Also has an online community where people can share experiences with other people affected by dementia.

### Assistive technology for memory problems

#### AT Dementia

**Tel** 0115 748 4220

**Email** [info@trentdsdc.org.uk](mailto: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](http://asksara.dlf.org.uk)**

#### Unforgettable.org

**Tel** 0203 322 9070

**Email**

[info@unforgettable.org](mailto:info@unforgettable.org)

**www.unforgettable.org**

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

### Support for carers

#### Carers Direct Helpline

**Helpline** 0300 123 1053

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

**www.nhs.uk/carersdirect**

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

**Tel (Scotland)** 0300 123 2008

**Tel (Wales)** 0292 0090 087

**Tel (Northern Ireland)**

028 9099 9476

**Email** [support@carers.org](mailto:support@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, 10am to 4pm)

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

**Email** advice@carersuk.org  
**www.carersuk.org**

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

### **Care regulators**

#### **The Care Quality Commission (CQC)**

CQC National Customer Service Centre, Citygate, Gallowgate, Newcastle upon Tyne NE1 4PA

**Tel** 03000 616161

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

#### **The Care Inspectorate Scotland**

Compass House,  
11 Riverside Drive, Dundee  
DD1 4NY

**Tel** 0345 600 9527

**Email** enquiries@careinspectorate.com

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

#### **Care and Social Services Inspectorate Wales**

Welsh Government Office,  
Rhydycar Business Park,  
Merthyr Tydfil CF48 1UZ

**Tel** 0300 7900 126

**Email** cssiw@wales.gsi.gov.uk

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

#### **The Regulation and Quality Improvement Authority**

9<sup>th</sup> Floor Riverside Tower,  
5 Lanyon Place, Belfast  
BT1 3BT

**Tel** 028 9051 7500

**Email** info@rqia.org.uk  
Registers and inspects a wide range of health and social care 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. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

#### **UK Council for Psychotherapy (UKCP)**

**Tel** 020 7014 9955

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

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

### **Emotional and mental health support**

#### **Mind**

**Helpline** 0300 123 3393

**Text** 86463

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

**www.mind.org.uk**

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

#### **Samaritans**

**Helpline** 116 123

**Email** jo@samaritans.org

**www.samaritans.org**

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** 0141 530 1000

(Mon to Fri, 9am to 5pm)

**www.samh.org.uk**

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

### **Support for older people**

#### **Age UK**

**Helpline** 0800 678 1174

(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**

information@redcross.org.uk

**www.redcross.org.uk**

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

#### **Disability Rights UK**

**Tel** 0207 250 8181

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

#### **Email**

enquiries@disabilityrightsuk.org

#### **www.**

**disabilityrightsuk.org**

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

### **Disabled Living Foundation (DLF)**

**Helpline** 0300 999 0004

(Tues to Thurs, 10am to 4pm)

**Email** helpline@dlf.org.uk

**www.dlf.org.uk**

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

### **LGBT-specific support**

#### **LGBT Foundation**

**Tel** 0345 330 3030

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

**Email** helpline@lgbt.foundation

**www.lgbt.foundation**

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

### **Financial or legal advice and information**

#### **Benefit Enquiry Line Northern Ireland**

**Helpline** 0800 220 674

(Mon, Tues, Wed and Fri, 9am to 5pm, Thurs, 10am to 5pm)

**Textphone** 028 9031 1092

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

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

#### **Citizens Advice**

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

#### **England**

**Helpline** 03444 111 444

**Email** debt.advice@citizensadvice.co.uk

**www.citizensadvice.org.uk**

**Wales**

**Helpline** 03444 77 2020  
**www.citizensadvice.org.uk/wales**

**Scotland**

**www.citizensadvice.org.uk/scotland**

**Northern Ireland**

**Helpline** 0800 028 1181  
**www.citizensadvice.co.uk/nireland**

**Department for Work and Pensions (DWP) Personal Independence Payment (PIP) Helpline**

0345 850 3322  
**Textphone** 0345 601 6677  
 (Mon to Fri, 8am to 6pm)  
**Carer's Allowance Unit**  
**Tel** 0345 608 4321  
**Textphone** 0345 604 5312  
 (Mon to Thurs, 8.30am to 5pm, Fri, 8.30am to 4.30pm)  
**www.gov.uk/browse/benefits**

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

**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.

**The Law Society**

113 Chancery Lane, London WC2A 1PL  
**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**

26 Drumsheugh Gardens, Edinburgh EH3 7YR  
**Tel** 0131 226 7411  
**Email** lawscot@lawscot.org.uk  
**www.lawscot.org.uk**

**Law Society of Northern Ireland**

96 Victoria Street, Belfast BT1 3GN  
**Tel** 028 9023 1614  
**www.lawsoc-ni.org**

**NiDirect**

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

**Advanced cancer and end-of-life care**

**Hospice UK**

**Tel** 020 7520 8200  
**Email** info@hospiceuk.org  
**www.hospiceuk.org**  
 Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

**Marie Curie**

**Helpline** 0800 090 2309  
 (Mon to Fri, 8am to 6pm, Sat, 11am to 5pm)  
**www.mariecurie.org.uk**  
 Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

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

# YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a template for handwritten text.

## Disclaimer

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

## Thanks

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

With thanks to: Lorraine Burgess, Macmillan Cancer and Dementia Nurse Consultant, The Christie Hospital; Dr Duncan Forsyth, Consultant Geriatrician; Professor Margot Gosney, Consultant in Elderly Care Medicine; Dr Karen Harrison-Dening, Head of Research and Evaluation, Dementia UK; and Dr Rachel Quibell, Consultant in Palliative Medicine.

Thanks also to The Great Camden Minds Dementia Engagement and Empowerment Project (DEEP) Group, the people affected by cancer who reviewed this edition, and those who shared their stories.

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

Alzheimer's Society. Dementia 2015: Aiming higher to transform lives.  
Alzheimer's Society. Information needs of people with dementia and carers. 2010.  
The Dementia Engagement and Empowerment Project (DEEP). Writing Dementia friendly information. 2013.

## Can you do something to help?

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

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



### Share your cancer experience

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

### Campaign for change

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

### Help someone in your community

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

### Raise money

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

### Give money

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

## Call us to find out more

**0300 1000 200**

[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

### Email

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

□□□□	□□□□	□□□□	□□□□
------	------	------	------

Valid from

□□	□□
----	----

Expiry date

□□	□□
----	----

Issue no

□□□
-----

Security number

□□□
-----

Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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