

A GUIDE FOR PEOPLE WITH CANCER AND DEMENTIA



Together with Macmillan



DementiaUK
Helping families face dementia

ABOUT ME

You can use this space to write down details you or your doctor may find useful.

My name _____

My carer's name _____

Carer's phone number _____

My condition Example: breast cancer and dementia

My cancer treatment Example: chemotherapy

My hospital's name _____

My medicines _____

My doctor's name _____

My doctor's phone number _____

Things I find helpful Example: writing things down

Other things to know about me _____

About this booklet

Some people who have cancer also have dementia. Having both conditions can be difficult for you and the people close to you.

The number of people living with both cancer and dementia is growing. We have written this booklet to:

- give people information about living with both conditions
- tell people where they may be able to get help.

This booklet gives information about living with cancer and dementia, but this is not the same as talking to your doctor. If you are worried about your health, talk to your doctor or nurse.

We have included quotes from people with dementia, which you may find helpful. These are from members of the Great Camden Minds Dementia Engagement and Empowerment Project (DEEP) group.

More information

Our booklet **Cancer and dementia – a guide for carers** has information for carers of people with cancer and dementia. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

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UNDERSTANDING CANCER

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What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up different parts of our bodies.

Cancer starts when normal cells go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more abnormal cells.

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

More information

We may be able to send you more information about the type of cancer you have. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free booklet.

Or you can visit our website at **macmillan.org.uk/information-and-support**

What is dementia?

Dementia is a term used to describe many different conditions. There are many types of dementia, so each person affected may have different symptoms. Alzheimer's disease is the most common type of dementia.

Dementia is damage to the brain. The symptoms depend on the type of dementia and which part of the brain is affected.

The most common symptoms are:

- problems remembering things
- problems thinking clearly
- finding it hard to solve simple problems.

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.



Being diagnosed with cancer

This diagram shows who you are likely to meet when you are diagnosed with cancer.

Family doctor (GP)

You will see your GP about your symptoms. If they think your symptoms could be caused by cancer, they will refer you to a specialist doctor.



Specialist doctor

A specialist doctor may be:

- a surgeon, who does operations
- an oncologist, who treats cancer with radiotherapy and chemotherapy.

Some people may see both.



Specialist nurses

Your specialist doctor can refer you to a specialist nurse. This may be:

- a clinical nurse specialist, who is an expert in the type of cancer you have. They also give information and support.
- palliative care nurse, who can help with symptoms caused by cancer, such as pain.

Some people may see both.

Treatments for cancer

The main treatments for cancer are:

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

The treatment you have will depend on:

- the type of cancer you have
- your general health
- any other conditions you have, such as dementia.

Your specialist doctors and nurses can talk to you about which cancer treatments might help.

More information

We have booklets about different cancer treatments. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free booklet.

Or you can visit our website to view the information online. Go to **macmillan.org.uk/treating**



Having chemotherapy

Your feelings about cancer and dementia

It is common to feel shocked, frightened or angry about your situation.

Talking about your feelings

It might help to talk to other people about how you feel. Some people find it hard to talk to close family and friends. If you would like to talk to someone else, your GP can refer you to a counsellor or support group.

Telephone support lines

You can contact the Macmillan Support Line on **0808 808 00 00** to talk things through with one of our cancer support specialists.

You could also call Dementia UK's Admiral Nurse Dementia Helpline on **0800 888 6678**. Or you can send an email to **helpline@dementiauk.org**

Online support

You may also find online communities useful. These are websites where people affected by cancer and dementia share their feelings and experiences.

Visit Macmillan's Online Community at **macmillan.org.uk/community** You can share your experiences of cancer, ask questions or just read through people's experiences.

Alzheimer's Society also has an online community called Talking Point. It is for anyone affected by dementia. Visit it at **forum.alzheimers.org.uk**

More information

Our booklet **How are you feeling? The emotional effects of cancer** has more information about coping with emotions. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.



DEMENTIA AND TREATMENT FOR CANCER

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Having treatment for cancer

Some people with cancer and dementia will be offered treatment for the cancer. If you do have treatment, you may spend some time in hospital.

Side effects of cancer treatment

You will probably have some side effects from cancer treatments. Your doctor or nurse will give you medicine to help.

The side effects don't usually last for a long time.

If you can't have cancer treatment

Some people may not be well enough for treatment because of other health problems.

Your doctor may talk to you about treatments that give a lower dose or fewer number of treatments.

If you decide not to have cancer treatment

Some people may choose not to have cancer treatment. If you decide this, your doctor or nurse will still give you treatment to help with symptoms, such as pain.

If the cancer treatment stops working

Sometimes the treatment stops working. If this happens, your doctor or nurse can still give you treatment to help with symptoms.



Giving your consent

Before you start treatment, your doctor will give you information about the treatment and its side effects.

The doctor will usually ask you to sign a form saying that you give permission for the hospital staff to give you the treatment. This is called consent.

No one can give you medical treatment without your consent.

Capacity

To give consent to have treatment, you must:

- be able to understand all the information
- be able to make an informed decision.

This is called capacity.

When you have dementia, your capacity can be affected. Your doctor may have to consider whether you can make an informed decision about treatment. If your capacity might be affected in the future, you can choose someone to make decisions for you.

It is useful to think about how you would like to be cared for in the future. Your doctors and specialist nurse can keep a record of your preferences. This means that they will know what to do if you are unable to make decisions in the future. We have more information on planning for the future on pages 20 to 21.



Planning for the future

Having dementia means there may come a time when you cannot communicate easily or make decisions for yourself. You may want to think about your future care and treatment.

Writing down your wishes

You can talk to your family or carers about how you would like to be cared for. Or you can write down your wishes and preferences. This means your family and healthcare professionals will know your wishes. These are called Advance Statements.

Power of Attorney

You may also want to nominate someone to make decisions for you in the future. You can give one or more people legal power to manage your affairs. This is called Power of Attorney.

Making a will

It is important to think about making a will. A will makes sure that people or issues that you care about are looked after. It also means that your wishes are carried out.

More information

Alzheimer's Society has a form called **This is me** that you and your carers can fill in. Healthcare staff can use it to understand more about your needs and wishes. You can download or order the form at **alzheimers.org.uk/thisisme** or by calling **0300 222 11 22**.

Dementia UK has a leaflet about Lasting Power of Attorney. You can download it from **dementiauk.org/planning-ahead** or order it by calling **020 7697 4160**.





LIVING WITH CANCER AND DEMENTIA

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Managing symptoms and side effects

You may have symptoms or side effects from cancer or its treatment. Your doctor or nurse can give you medicine or advice to help with these.

Memory or concentration problems

Some people having treatment for cancer may have memory problems. They may also feel very tired. 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 chemo brain. It is usually temporary and should get better with time.

Appetite changes and eating problems

People can have appetite changes or eating problems. Some people may struggle to eat enough. Others may eat more than usual and put on weight.

Eating and drinking well may help prevent problems like constipation and dehydration.

Tips to help you eat well:

- Eat plenty of high-fibre foods like fruit and vegetables.
- Drink plenty of fluids during the day.

If you are struggling to eat enough, talk to your doctor or nurse. They may refer you to a dietitian. Dietitians give advice on what to eat and whether nutritional supplements may help.

Constipation

People with cancer and dementia are more likely to become constipated.

Tips to help you avoid or improve constipation:

- Eat plenty of fruit, vegetables and high-fibre foods. This will help keep your bowels moving.
- Drink about 2 litres (3.5 pints) of fluids a day. This will help keep your bowels regular. It will also stop you from becoming dehydrated.
- Keep active. Even some very gentle exercise at home can help with constipation.

If constipation is a problem, tell your GP, nurse or carer. They may give you medicines to help.

Pain

Some people have problems with pain. If you are in pain, painkillers can usually help. These can be:

- tablets or capsules
- patches that stick to the skin.

Doctors can adjust the dose of medicines or try new ones.

Other things you or your carer can do to help is to:

- change your position
- use heat pads or hot-water bottles
- use ice packs
- massage the painful area.

Sometimes you may need specialist help for your pain and symptoms.

You may have a short stay in a hospital or hospice to assess the pain and control it better. Once your symptoms are better, you will be able to go home again.

Sleep problems

You may find it hard to sleep at night. Keeping physically active during the day may help you sleep at night. If you can, try to do some gentle exercise at home.

If you cannot sleep because you feel unwell or are in pain, talk to your GP or specialist nurse. They may be able to give you medicines to help.

If you are uncomfortable at night, your nurse may be able to get equipment that may help. For example, a pressure-relieving mattress.

Using a symptom diary

You may find it useful to note down your symptoms using the symptom diary opposite. You can write down any symptoms you have and what helps. You may want to show your notes to your doctor so they can help you.

More information

Our booklets **Managing the symptoms of cancer** and **Side effects of cancer treatment** have more information about common symptoms and side effects. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.



Looking after yourself

There are some things that you can do to help yourself. This may help you feel more in control of your situation.

Dementia UK's Admiral Nurse Dementia Helpline can give you more information about keeping well when you have dementia and cancer. You can call them on **0800 888 6678**.

Eat well and keep to a healthy weight

It is common for someone with cancer and dementia to have eating problems or struggle to stay at a healthy weight.

Tips to help you eat well:

- Eat plenty of high-fibre foods like fruit and vegetables.
- Drink plenty of fluids during the day.

Many people with cancer and dementia find that there are times when they can't eat as much as usual, and sometimes they lose weight.

If you find it difficult to eat enough, you may find it helpful to read our booklets **The building-up diet** and **Recipes for people affected by cancer**.

Look after your health

- Take medicines that your doctor or nurse gives you. Check the prescription label for how to take them.
- Ask your pharmacist to put your medicines in a pill organiser (dosette box). This is marked with the times you should take the medicines.
- Have regular check-ups with your GP or practice nurse.
- If you feel unwell, don't wait for symptoms to go away. Make an appointment with your GP.
- Keep up to date with hearing, eye and dental checks.
- Ask your pharmacist or GP about the flu jab.

Using a dosette box



Keep active

Being physically active can help improve a poor appetite and constipation. It may also help you sleep better.

Tips for keeping physically active:

- Try to reduce the amount of time you spend sitting or lying down. Just moving around the house and doing simple day-to-day things will help.
- You may be able to do gentle stretching exercises.
- Start slowly and gradually build up the amount of physical activity you do.
- Check with your GP whether there are any physical activities that you should not do.



Alcohol

If you have confusion, alcohol can make it worse. It is important to limit how much alcohol you drink.

If you are taking regular medicines for cancer or dementia, check with your GP or pharmacist whether it is safe to have alcohol.

Smoking

If you smoke, you should try to stop. Smoking can increase your risk of bone thinning, some cancers and heart disease.

Memory problems

Memory problems can be worrying and frustrating. Tips that you may find helpful:

- Keep to routines.
- Only do one thing at a time.
- Make lists and tick off completed tasks.
- Try to do things in a quiet place with no distractions.
- Break information into small chunks to help you remember it.
- Write down important things.

Aids for memory problems

You might be able to get aids to help you to stay independent and improve safety in your home. These may be things like:

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

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

Jean, a member of the Great Camden Minds DEEP group

More information

Alzheimer's Society has a book called **The memory handbook: a practical guide to living with memory problems**. You can download it or order a copy at **alzheimers.org.uk** or by calling **0300 222 11 22**.

Age UK has a leaflet called **Strength and balance exercises for healthy ageing**. It has information about exercises that you can do at home. You can download it or order a copy at **ageuk.org.uk** or by calling **0800 678 1174**.

We have booklets about healthy living that you may find helpful. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy of:

- **Giving up smoking**
- **Physical activity and cancer**
- **Eating problems and cancer.**

In this booklet, page 53 in the section 'Other useful organisations' has details about where you can get memory aids.

Dementia UK has a range of leaflets on managing your health after being diagnosed with dementia. You can download them at **dementiauk.org/maintaining-health** You may also find it helpful to speak to one of their Admiral Nurses. You can call them on **0800 888 6678** or email **helpline@dementiauk.org**



GETTING SUPPORT

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Who can help?

People who may be able to support you include:

- family, friends and neighbours
- doctors, nurses and social workers.

Before you talk to someone, it can help to prepare some questions you might like to ask. You could take a family member or friend with you to appointments to help you remember what was said.

The type and amount of support you get will depend on where you live.

'Know what is available. For example, a district community nurse may be able to come to the house to help give you your medicines.'

Bill, a member of the Great Camden Minds DEEP group

Professionals who can help

GP (family doctor)

This doctor looks after people who are unwell and being looked after at home. They can refer you to other services, such as nurses and social workers.

District nurse

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

Specialist nurses

Specialist nurses can give information and support about certain diseases. They do not usually provide nursing care.

Admiral Nurses

Admiral Nurses are specialist dementia nurses. They help families face dementia with more confidence and less fear.

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

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

Social workers

A social worker helps decide what practical and social help you or your carer need. Your GP or a nurse can refer you to a social worker.

Help at home

Carers can come to your home to help. The type of help they give will vary depending on where you live.

Voluntary organisations and charities

Voluntary organisations and charities offer help, such as:

- giving information
- loans of equipment
- grants
- transport
- volunteers who can be with you, to give your carer a break.

Your district nurse, specialist nurse or GP can refer you to any of the professionals or voluntary organisations that we have mentioned.





Palliative care

What is palliative care?

Palliative care is treatment to help manage symptoms and improve quality of life. Sometimes cancer treatments like radiotherapy are used in palliative care. This can help with symptoms, such as pain.

Palliative care teams include specialist nurses and doctors. These teams specialise in:

- controlling pain and symptoms
- offering emotional support.

Having palliative care

Community palliative care teams are sometimes based in hospices. But they can also visit people who are being cared for at home.

Some people may have help from a palliative care team from when they are first diagnosed with cancer. Others may meet the team later.

If you have symptoms that are hard to control, you may have a short stay in a hospice. Once symptoms have improved, you can go home again.

End of life

Many people with cancer get better, but others will not. Hearing that you may be nearing the end of your life can be very difficult.

Your feelings

You may have strong emotions that are difficult to cope with. You may need some time on your own or with someone close who you can talk to about your feelings.

Getting support

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, specialist nurse or social worker.

You may also find it helpful to speak to one of Dementia UK's Admiral Nurses. Call them on **0800 888 6678** or email **helpline@dementiauk.org**

Planning for the future

Although your future may be uncertain, you can still make the most of times when you feel well. There may be important things you want to think about. For example:

- where you want to be cared for
- making a will
- choosing someone to make decisions for you if you are unable to.

More information

In this booklet, the section called 'Planning for the future' on pages 20 and 21 has more information about:

- making decisions for future care
- making a will.

Our booklet **End of life: a guide** has more information about end of life. It is aimed at people in the final stages of life, and their carers. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Financial help and benefits

You may be entitled to financial help if:

- your income is low
- you are struggling to cope with the financial effects of cancer.

More information

Call our financial guides or welfare rights advisors on **0808 808 00 00**. They can help you access benefits and financial support.

Our booklet **Help with the cost of cancer** has more detailed information about benefits. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

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

Some other organisations can also offer help with financial issues. We have listed some organisations on page 53.



A Macmillan financial guide



FURTHER INFORMATION

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About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** 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**

There you will 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**

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 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 to Sun, 9am to 5pm)

Email [helpline@
dementiauk.org](mailto:helpline@dementiauk.org)

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

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.

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

Helpline 0300 222 11 22

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

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.

Aids for memory problems

Unforgettable

Tel 0203 322 9070

Email

info@unforgettable.org

www.unforgettable.org

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

Financial or legal advice and information

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 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.org.uk/nireland

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.

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 lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for student input.

SYMPTOM DIARY

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CANCER SUPPORT

WE ARE
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SYMPTOM DIARY

Before you write in this diary, you or someone else could make a copy.

What is the symptom?

I feel sick

When do you have
the symptom?

After I eat

You can use this diary to write down any symptoms you have and what helps. If you want to, you could show this to your doctor. They may be able to give you more advice about managing symptoms.

That way you can use it as often as you need to.

How does it feel?

Tummy ache

What helps?

Peppermint

SYMPTOM DIARY

You can use this diary to write down any symptoms you have and what helps. If you want to, you could show this to your doctor. They may be able to give you more advice about managing symptoms.

Before you write in this diary, you or someone else could make a copy. That way you can use it as often as you need to.

| What is the symptom? | When do you have the symptom? | How does it feel? | What helps? |
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Disclaimer

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

Thanks

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With thanks to: Lorraine Burgess, Macmillan Cancer and Dementia Nurse Consultant; Dr Duncan Forsyth, Consultant Geriatrician; Professor Margot Gosney, Consultant in Elderly Care Medicine; Dr Karen Harrison-Dening, Head of Research and Publications, 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 and dementia who reviewed this edition, and those who shared their stories.

Sources

We have listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at **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 National Institute for Health and Care Excellence (NICE). Dementia: Supporting people and their carers in health and social care. 2016.

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

This booklet is about cancer and dementia. It is for anyone who has both cancer and dementia.

It explains what may happen after you are diagnosed with cancer. It also has practical advice about ways to look after yourself when you have cancer and dementia.

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**



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**, Monday to Friday, 9am to 9pm, and Saturday to Sunday, 9am to 5pm, or visit **dementiauk.org**

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What's this logo? Visit **macmillan.org.uk/ourinformation**

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