MACMILLAN CANCER SUPPORT

A guide for people with cancer and dementia



Created in partnership with

DementiaUK
Helping families face dementia

About this booklet

This booklet is about cancer and dementia. It is for anyone who has both cancer and dementia. We have written it in partnership with Dementia UK.

The number of people living with both cancer and dementia is growing. Having both conditions can be difficult for you and the people close to you.

We have written this booklet to:

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

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 you. You should talk to your doctor, who knows your medical history.

Our booklet **Cancer and dementia – a guide for carers** has information for carers of people with cancer and dementia (page 46).

How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you. You may find it helpful to read this booklet with a family member, friend or carer.

On pages 52 to 59, there are details of other organisations that can help.

On page 60 there is space to make notes about you and your diagnosis, and for any questions you might want to ask your doctor.

For more information

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

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

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

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

The language we use

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

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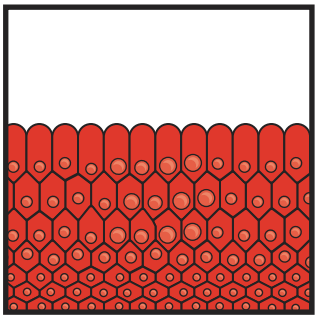
What is cancer?

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

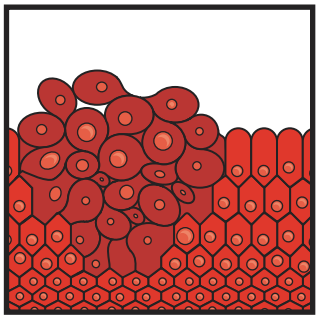
Cancer starts when something goes wrong with a normal cell and it becomes abnormal. The abnormal cell keeps dividing, making more abnormal cells.

These abnormal cells can form a lump. This is called a tumour. Sometimes blood cancers develop when blood cells become abnormal. Sometimes cancer cells spread to other parts of the body.

Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Being diagnosed with cancer

When you are diagnosed with cancer, here are some of the people you may meet to help you.

GP (local doctor)

You will meet with 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 is an expert in a specific area of the body. They will usually do some tests. If they diagnose cancer, they may refer you to:

- a surgeon, who does operations
- an oncologist, who treats cancer with different treatments, such as chemotherapy
- a palliative care doctor, who can help treat symptoms of cancer, such as pain.

You may meet with more than one type of doctor.

Specialist nurses

A specialist doctor can refer you to a specialist nurse, such as:

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

You may meet with more than one type of specialist nurse.

Cancer and dementia

If you have dementia, you may already have support from a specialist doctor or nurse. These may include:

- a psychiatrist with experience in dementia
- a doctor specialising in elderly care (geriatrician)
- a doctor specialising in the brain and nervous system (neurologist)
- a nurse who is an expert in different types of dementia (Admiral Nurse) – they can also give information and support.

If you would like support from an Admiral Nurse, Dementia UK has more information (page 52).

We have more information about different types of cancer.

You can order our booklets and leaflets for free. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.



Treatments for cancer

The main treatments for cancer are:

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

The treatment you have will depend on:

- the type of cancer
- 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.

We have more information about different cancer treatments on our website at **macmillan.org.uk/treatment-types**

We also have easy read booklets about some of these types of treatments. These booklets use simplified information and illustrations to explain different cancer treatments. You can find them on our website at **macmillan.org.uk/easy-read**

Your feelings about cancer and dementia

It is common to feel shocked, frightened or angry about having cancer and having dementia.

Talking about your feelings

It might help to talk to other people about how you feel. You could talk to close family members and friends. If you find this hard, you might like to talk to someone else. Your GP may refer you to a counsellor. This is someone who is trained to listen to people's problems and help them find ways to cope.

Telephone support lines

You can contact the Macmillan Support Line on **0808 808 00 00**.

You can also call Dementia UK's Admiral Nurse Dementia Helpline on **0800 888 6678**, or find out more on the Dementia UK website at **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 other people's experiences.

Alzheimer's Society has an online community called Talking Point. It is for anyone affected by dementia. There is also a support forum for people and families affected by both dementia and cancer.

You can find out more about these on the Alzheimer's Society website at **alzheimers.org.uk**

More information about feelings

We have more information about coping with emotions in our booklet and audiobook **How are you feeling? The emotional effects of cancer** (page 46).

This information is not specifically about cancer and dementia, but you might find it helpful. You may like to read this information with your carer, family member or friend.

Dementia UK also has information about the emotional impact of dementia on their website at **dementiauk.org/emotional-impact-of-a-diagnosis**



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Having treatment for cancer

After a cancer diagnosis, your cancer doctor or nurse will talk to you about treatment options. If you have treatment, you may spend some time in hospital. It is important that the healthcare team know you have dementia.

You may want to have someone with you at the hospital. This could be a carer, family member or friend. They can support you and help the healthcare team take care of you when you are in hospital or attending appointments. Your cancer doctors, nurses and healthcare team can talk to you more about this.

Going to your appointments

When you have your treatment, you might find it helpful to:

- have appointments at a time of day that is best for you
- use a parking space close to the hospital entrance, if possible
- have family or friends sit with you on hospital transport and during treatment.

Side effects of cancer treatment

You will probably have some side effects from cancer treatments. You can ask your cancer doctor or specialist nurse about this. They will give you medicines to help.

The side effects do not usually last for a long time.

If you cannot have cancer treatment

Some people may not be well enough for treatment because of other health problems. Your cancer doctor or specialist nurse will explain more about the risks of treatment if you have other health problems.

Your cancer doctor may talk to you about treatments where you have lower doses of medicine or fewer treatment sessions.

Deciding not to have cancer treatment

Some people choose not to have cancer treatment. If you decide this, your cancer doctor or nurse will still offer you treatment to help with the cancer symptoms.

If cancer treatment stops working

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

Giving your consent

Before you start treatment, your cancer doctor, nurse and healthcare team will give you information about the treatment and its side effects. You may want someone with you when you are being given information about the cancer and how it will be treated.

You could ask your cancer doctor or nurse how your dementia might affect you during different treatments.

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

Or your consent can be a spoken agreement with your doctor. Your doctor will record this in your medical notes.

If you are not able to give consent, your cancer doctor can still give you treatment if they think it is in your best interests.

Capacity

To give consent to have treatment, you must be able to:

- understand all the information the doctor gives you about the treatment
- remember the information long enough to make a decision
- consider the benefits and risks of treatment
- make an informed decision
- communicate your decision by talking, using sign language or any other means.

If you are able to do these things, this is called having capacity.

When you have dementia, your capacity can be affected. It is normal for your cancer doctor to ask you some questions to check whether you can make an informed decision about your treatment.

You can find out more about giving consent on our website at **macmillan.org.uk/treatment-consent**

Planning for the future

Having dementia means there may be a time when you cannot communicate easily or make decisions for yourself. You may want to think about your future care and treatment. You can talk to your family or carers about how you would like to be cared for. Or you may choose to write things down.

Advance care planning

Advance care planning is a record of your wishes about your future care and support. It includes decisions about medical treatment and end of life care. Talking with your health and social care team and those you trust will help them understand what is important to you. If you are unable to make decisions in the future, your wishes can still be followed.

Making an advance care plan is sometimes known as an advance statement.

Dementia UK has more information about advanced care planning, including an advance care plan template. You can find out more on their website at **dementiauk.org**

Power of attorney

You may also want to name someone to make decisions for you in the future. These may include decisions about your:

- health and welfare
- property and finances.

You can give 1 or more trusted people legal power to manage your affairs. Depending on where you live, this may be called:

- lasting power of attorney
- continuing power of attorney
- enduring power of attorney.

A power of attorney can only be used if you are unable to make decisions.

Dementia UK has more information about lasting power of attorney on their website at **dementiauk.org**

Making a will

It is important to think about making a will. A will makes sure that the people or things you care about are looked after when you die. It also means that your wishes are followed.

You can find out more on our website at **macmillan.org.uk/writing-a-will**

Dementia UK also has advice and guidance on writing and updating a will on their website at **dementiauk.org/write-or-update-your-will-for-free**



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Managing symptoms and side effects

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

Memory or concentration problems

Cancer treatment may cause memory problems. You may also feel very tired. This is called chemo brain. It may feel different to the memory problems caused by dementia. Although it is called chemo brain, these side effects can also happen when you are having other types of cancer treatment.

People with dementia are more likely to have this side effect. It is usually only for a short time and should slowly improve. But for some people, symptoms can continue for a while after treatment.

Constipation

Some cancer treatments can cause constipation. Constipation means that you are not able to empty your bowels (poo) as often as you normally do. It can become difficult or painful.

Here are some tips that may help:

- Drink about 2 litres (8 glasses) of fluids a day. This will help keep your bowel movements regular. It will also stop you becoming dehydrated.
- Eat high-fibre foods such as fruit, vegetables and wholemeal bread.
- Do regular gentle exercise, such as going for a short walk, if you can.

If constipation is a problem, tell your GP, nurse or carer. There may be medicines that can help.

Pain

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

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

If the painkillers you are taking are not working for you, doctors can adjust the dose of medicines or try new painkillers.

You or your carer can also help manage pain by:

- changing your lying or sitting position regularly
- using heat pads or hot water bottles on the painful area
- using ice packs on the painful area
- massaging the painful area.

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

You may stay in a hospital or hospice for a short time to assess the pain and control it better. When your symptoms are better, you can go home again.

Sleep problems

You may find it hard to sleep at night. Keeping physically active during the day may help you sleep. 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 if you can. They may be able to give you medicines to help.

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

Using a symptom diary

If you can, you may find it useful to write down your symptoms using a symptom diary (pages 26 to 27). 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 about symptoms and side effects

We have more information about managing the symptoms of cancer and side effects of cancer treatment in our booklets **Managing the symptoms of cancer** and **Side effects of cancer treatment** (page 46).



Symptom diary

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

What is the symptom?	When do you have the symptom?	

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.

	How does it feel?	What helps?

Looking after yourself

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

Sometimes you may need the help of others such as a carer, family member or friend.

Dementia UK's Admiral Nurse Dementia Helpline can give you more information about keeping well when you have dementia and cancer. You can call the helpline on **0800 888 6678**. There is more information on page 52.

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.

Eating well and drinking enough may help prevent problems such as constipation and dehydration.

It may help to:

- eat plenty of high-fibre foods such as fruit and vegetables
- drink plenty of fluids during the day.

Many people with cancer and dementia have times when they cannot eat as much as usual. Sometimes they lose weight. If you are struggling to eat enough, talk to your cancer doctor, specialist nurse or member of your healthcare team. They may refer you to a dietitian. Dietitians give advice about what to eat and whether nutritional supplements may help.

If you find it difficult to eat enough, you may find it helpful to read our booklet or listen to our audiobook **The building-up diet** (page 46).

You may have eating problems caused by a sore or dry mouth. We have more information about mouth care at **macmillan.org.uk/mouth-problems**

Look after your health

While living with cancer and dementia, it is important to look after your general health as much as possible. This may help stop some problems in the future. You might find the following tips useful. You may like someone to help you with these:

- Take the medicines that your GP, specialist doctor or specialist nurse gives you. Check the prescription label for instructions on 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, do not wait for symptoms to go away. Make an appointment with your GP.
- If you are having treatment for cancer, you can contact the hospital on the number you have been given.
- Keep up to date with hearing, eye and dental checks.
- It is important to ask your GP, cancer doctor, nurse or pharmacist for advice about having vaccinations. They can explain what vaccines are right for you and when it is best to have them.

Keep active

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

Here are some 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 everyday things will help.
- You may be able to do gentle stretching exercises.
- Start slowly and gradually increase the amount of physical activity you do.
- Check with your GP or specialist nurse if there are any physical activities 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 drink alcohol.

Smoking

Stopping smoking is the most important thing you can do for your health. If you smoke, you should try to stop. Smoking can increase your risk of bone thinning, some cancers and heart disease. During cancer treatment, stopping smoking may help the treatment work better. It may lower the risk of certain cancers coming back after treatment.

Your GP, cancer doctor or nurse can give you more information.

The NHS has a lot of information and support to help you give up smoking. You can find these details and other organisations who can help on pages 55 to 56. Or you can check the NHS website at **nhs.uk** for services in the country where you live.

Memory problems

Memory problems can make it difficult if you have cancer. Here are some tips you may find helpful:

- Keep a note of routines and appointments. You could write them down on a wall calendar. Keep it in a place that you will see often. Or set reminder alerts on your mobile phone.
- Write down any symptoms or side effects you have – you could use our symptom diary on pages 26 to 27.
- Write down the name and telephone number of your cancer doctor or specialist nurse. Leave this information by the phone. Or save the contacts in your mobile phone.

Aids for memory problems

You might be able to get aids to help you to stay independent and make your home safer. These may be things such as:

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



More information about living with cancer and dementia

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 free copy by post. Search 'memory handbook' on the Alzheimer's Society website at **alzheimers.org.uk**

We have information about healthy living in our booklets, which you may find helpful:

- **Physical activity and cancer**
- **Eating problems and cancer** – this is also available as an audiobook.

You may like to read them with someone, such as a family member.

Dementia UK has a range of leaflets including managing your health after being diagnosed with dementia. You can search for these leaflets on their website at **dementiauk.org**

Dementia UK has Admiral Nurse clinics. These are for people with dementia, or family carers. You can speak with a specialist dementia nurse in person, by video link or telephone. You can book a time that suits you.

You can find out more on the Dementia UK website at **dementiauk.org/admiral-nurse-clinics**

You can order our booklets and leaflets for free. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.





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Who can help?

People who may be able to support you include:

- family members, friends and neighbours
- doctors, nurses and other members of the health and social care team.

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 available will depend on where you live.

Professionals who can help

You may meet with the following professionals.

GP (local doctor)

GPs look after people who are unwell and being cared for at home. They can refer you to other services, such as nurses and social workers.

District nurses

District nurses work closely with GPs. They give advice and support to people by visiting them at home. If needed, they can visit you regularly.

Specialist nurses

Specialist nurses can give you information and support. They are experts in certain diseases. They do not usually provide nursing care.

Admiral Nurses

Admiral Nurses are specialist dementia nurses. They help families by giving them one-to-one support, expert guidance and practical solutions.

Admiral Nurses work in:

- GP practices
- NHS hospitals
- care homes and hospices.

To find out whether there is an Admiral Nurse in your area, call the Admiral Nurse Dementia Helpline on **0800 888 6678**.

Social workers

Social workers help you 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 may depend on where you live. Some may help with domestic jobs, such as cooking and shopping. Others may only help with personal care, such as washing and dressing.

Voluntary organisations and charities

Voluntary organisations and charities offer help, such as:

- information or help with getting further support
- loans of equipment
- grants
- transport
- volunteers who can be with you, to give your carer a break (respite care).

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

Palliative care

Palliative care is treatment to help manage symptoms and improve quality of life. Sometimes cancer treatments such as 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 stay in a hospice for a short time. When your symptoms are better, you can go home again.

End of life

Many people with cancer get better, but others do not. Learning 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 (page 37).

Planning for the future

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

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

More information about planning for the future

We have more information about planning for the future on pages 18 to 19. This includes helpful tips on:

- making decisions for future care
- making a will.

We also have more information on our website at **macmillan.org.uk/advance-care-planning** and in our booklet and audiobook **A guide for the end of life** (page 46).

Dementia UK has information about planning for the future on their website at **dementiauk.org/advance-care-planning**

Financial help and benefits

A diagnosis of cancer and dementia can change your financial situation. It may mean you or a family member need to stop working, or work less. It can also mean spending more money on things such as hospital parking. You may be able to get financial help if:

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

More information about financial help and benefits

If you want to talk things through, you can call our money advisers on **0808 808 00 00**.

Our booklet and audiobook **Help with the cost of cancer** has more detailed information about benefits (page 46). You may like to read this information with a carer, family member or friend.

Dementia UK also has financial advice for people affected by dementia (page 52).

Some other organisations can offer help with financial issues (pages 56 to 57).

We have more information about how Macmillan can help with money worries on pages 49 to 50.



MACMILLAN

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About our information

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

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

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

The language we use

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

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

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and find the options and opening times.

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial advice

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

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 0000**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

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

Talk to others

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

Support groups

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

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**

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

Macmillan healthcare professionals

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

Other useful organisations

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

Support for dementia

Dementia UK

Helpline **0800 888 6678**
www.dementiauk.org
Provides practical and emotional information and support to people with dementia and anyone affected by dementia. Services include a free helpline staffed by dementia specialist Admiral Nurses who provide information, advice and support with any aspect of dementia, including Alzheimer's disease.

You can also book a virtual clinic appointment to discuss any questions or concerns with an Admiral Nurse by phone or video call at a time that works for you.

Alzheimer Scotland

Helpline **0808 808 3000**
www.alzscot.org
Provides a range of services for people with dementia and their carers, including personalised support services, community activities, information and advice.

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

Dementia Support Line **0333 150 3456**
www.alzheimers.org.uk
Provides a free helpline, and written information about dementia, treatment and living with dementia. Use the dementia directory to find local support services for people with dementia and their carers in England, Wales and Northen Ireland. Use the online community to share experiences with other people affected by dementia.

Relish

www.relish-life.com
Offers products, activities and well-being resources for people with dementia.

General cancer support organisations

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

General health information

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

www.111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way (Scotland)

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service.
Offers advice and information about how to stop smoking.
You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 278 6119**
Text '**HMQ' to 80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking.
Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling.
The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

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

Advanced cancer and end of life care

Compassion in Dying

Helpline **0800 999 2434**
www.compassionindying.org.uk
Provides support for making informed choices and starting honest conversations about death and dying. Also provides guides on setting up a will, power of attorney and advance statement.

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Your notes and questions

You can use this space to write down details about you and your diagnosis, questions you want to ask your doctor, and any other notes.

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

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

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

Sources

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

National Institute for Health and Care Excellence (NICE). Decision-making and mental capacity. NICE guideline [NG108]. Published 3 October 2018. Available from: www.nice.org.uk/guidance/ng108 [accessed June 2023].

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

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN CANCER SUPPORT

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

If you are a carer, we have a separate booklet called Cancer and dementia: a guide for carers.

The booklet 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.

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

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

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

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

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