

Planning ahead



**Alzheimer's
Society**

It will take a society to beat dementia



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There's No Place Like
Nanny's House
♥♥♥



Planning ahead

If you have been diagnosed with dementia, this booklet is for you. It will help you plan ahead and think about what may happen in the future.

It's important to plan ahead because dementia is a progressive condition. This means there may come a time when you find it hard to make decisions for yourself. By making some decisions now, you might find that you feel more prepared and in control of your future.

Planning ahead can also help your family and friends, especially if you become ill or less able to communicate. If they know what you want to happen in the future, they can support your wishes.

This booklet explains some ways you can plan ahead. It can help to think about these as soon as you feel able to and while you have the ability (known legally as 'mental capacity') to make decisions about the future.

1



Doing what you can

2 As dementia is a condition that gets worse over time, you may need more support in the future. This could be someone helping you to manage your finances or making medical decisions on your behalf. Talking about your wishes through to end of life can help others understand and respect those wishes. However, it can be difficult to think and talk about the future. There is no right or wrong way to do this. Some people find knowing what will happen reassuring, while others would rather not think about it.

Where to start

By reading this booklet, you have already made a step towards planning ahead for your future. It might feel like there's a lot to think about, but you don't have to read it all at once. Read sections as and when you feel ready. You can also ask someone you trust to support you while you read.

You might also find it helpful to spend some time alone to gather your thoughts about what you want to happen in the future. When you feel ready you can share these thoughts with people close to you.



Talking to others about your future

When you feel like the time is right, you might decide to talk to someone else about your plans and ideas for the future. That person could be a family member, friend or carer. It's important to make sure it is someone you trust. The tips below are there to help you and other people talk about your future.

- **Read this booklet together.** The information in this booklet is about the decisions you may need to think about following a dementia diagnosis. Knowing what these decisions are can help shape your conversation.
- **Take your time.** You don't have to tackle everything in one conversation. Only talk about what you feel ready to discuss.
- **Be honest.** Sharing how you think and feel helps others understand what you want for the future.
- **Don't feel pressured.** There might be topics in this booklet that you'd rather not discuss. That is your decision to make and you don't have to talk about something if you don't want to.
- **Know that the people you talk to are there for you.** The conversation might feel emotional or difficult for everyone involved but each person is there to support your wishes and help you prepare for the future.

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If you decide to take some of the steps mentioned in this booklet, you need to have mental capacity to do so. Because dementia gets worse over time, it makes sense to start as soon as you can.



For more information on mental capacity, see factsheet **460 Mental Capacity Act 2005**. For more information about mental capacity in Northern Ireland see www.health-ni.gov.uk/mca

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Getting your paperwork in order

A practical way to start is to go through all your financial and personal paperwork and put it in order so that you can access it easily. This might include information about:

- your bank accounts, pension, tax, any benefits you receive and insurance policies
- the property you live in and any other property you own
- any medication you are taking and hospital clinics you may attend
- any gifts you have made
- your will if you have made one.

You might find it helpful to ask a friend or family member you trust to help you with this. Getting your paperwork organised will also be helpful for them or anyone else who looks after your affairs in the future.



Getting support

If you need to speak to someone about the topics covered in this booklet, our dementia advisors are available to listen, and to give support and advice. You can contact our Dementia Support Line by calling **0333 150 3456** seven days a week. If you speak Welsh, call our Welsh-speaking support line on **03300 945 400**.

If you have speech or hearing difficulties and have a textphone or an adapted computer, you can use Text Relay to call our English-speaking dementia support line on **18001 0300 222 1122**.

2





Powers of attorney

There may come a time when you need someone to make decisions for you. If you live in England or Wales, a Lasting power of attorney (LPA) is a legal document that allows you to appoint someone you trust to do this. You can choose who you appoint to act for you (the 'attorney'). They might be a partner, family member or a friend and you can decide what decisions they can make for you. You can also choose to appoint more than one attorney.

You can also appoint a 'professional attorney', such as a solicitor or accountant. This might be useful if you want someone independent of your family, or if your finances are complicated. Bear in mind, however, that they will charge for their services. You need to have mental capacity to make an LPA so it is a good idea to think about making one as soon as you feel able.

Creating an LPA can help you and those close to you in the future. The attorney has to do what is best for you and they must always think about your wishes and needs. They should also still keep you involved as much as possible.

There are two types of LPA, depending on the decisions you want the attorney to make.

3



Property and financial affairs LPA

A property and financial affairs LPA covers things like paying bills, managing bank accounts and selling property.

This LPA can work in two different ways, depending on which option you choose:

- One option is to allow the attorney to only make decisions when you can't make them yourself.
- The other option is to allow the attorney to make decisions with your consent, even if you can make them yourself. This can be a good way to give yourself some extra support.

Health and welfare LPA

A health and welfare LPA covers decisions about things like your day-to-day care and medical treatment, including life-sustaining treatment if you specify that.

This LPA will only allow the attorney to make decisions when you can't make those decisions yourself.



For more information on LPAs, see factsheet 472 **Lasting power of attorney.**



If you don't have access to the internet or you don't feel able to complete the LPA forms on a computer, Alzheimer's Society offers a service that can help you. Our trained volunteers can complete the forms on your behalf using the Office of the Public Guardian's (OPG) online tool. For more information on this service, call our support line on **0333 150 3456**. This service doesn't provide legal advice.

Some people find it helpful to use a solicitor to help them make an LPA. If you decide to do that, make sure you get a clear idea of how much it will cost.

Enduring power of attorney

If you live in Northern Ireland you can create an Enduring power of attorney (EPA). An EPA only gives the attorney the power to make decisions about your finances and property. It does not cover decisions about your health and welfare. You need to have mental capacity to make one.

An EPA comes into effect from the moment it is signed and, provided it is registered with the Office of Care and Protection, will still be effective if you later become unable to manage your affairs. This flexibility can be helpful if, for example, you are in hospital or need extra support dealing with things like paying bills.

3



If you do not want your attorneys to act on your behalf until you have lost the mental capacity to make your own decisions, then you can include a restriction in your EPA preventing that. If you are considering making an EPA, then you should seek independent legal advice. It is not possible to make an EPA online.



For more information, see factsheet NI472
Enduring power of attorney and controllership.

3

Before October 2007, it was possible to make an EPA in England and Wales. It is a good idea to check your paperwork to see if you made an EPA in the past that will still work for you. For example you might have made one at the same time as you made a will. It will only cover your property and finances, not your health and welfare.



I think it's entirely sensible to forward plan... I would start with making a will and granting LPA.

Person with dementia



For more information visit [alzheimers.org.uk](https://www.alzheimers.org.uk)



General and Ordinary power of attorney

You may come across something called a General or Ordinary power of attorney, which can be used to allow someone else to make decisions about your property or finances. However, unlike an LPA or EPA, these will not be effective if you lose mental capacity to make those decisions in the future yourself. That is why an LPA (or EPA in Northern Ireland) is the appropriate document to use if you have dementia.



Call our Dementia Support Line on **0333 150 3456**

What happens if you don't make an LPA or EPA for property and financial affairs

You may become unable to manage your property and finances in the future. If you don't make a property and financial affairs LPA (or an EPA in Northern Ireland), there may come a time when no one can legally do that for you. This can make it difficult to do things like pay your bills or care costs. If this happens, someone such as a partner or family member, may need to apply to the Court of Protection to become your deputy.

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If you live in Northern Ireland, they will need to apply to become your controller with the Office of Care and Protection.

The processes to set up a controller or deputy take longer and are more expensive than making an LPA or EPA. The court will also choose who is appointed as the controller or deputy, not you.



For more information, see factsheet **530 Deputyship**, and for Northern Ireland see factsheet **NI472 Enduring power of attorney and controllership**.

See 'Future and end of life care planning' on pages 23-25 for information about what happens if you don't or can't make an LPA for health and welfare.



Trusts

If you have assets such as property or savings, you may be able to set up a trust. This will make sure your money is used how you want it to be. The trust could also include the money you will use to pay for your care or where you live in the future.

Setting up a trust involves making a legal document that allows someone else to manage your assets for you, in line with your wishes. You need to have mental capacity to set one up.

There are several types of trust and different ways to arrange them. Setting up a trust can be complicated and expensive because there are specific rules attached to them. There are also complicated tax issues to think about. You will normally need a professional to help you, so if you're thinking of setting one up, you should talk to a solicitor.

4



Advance decision to refuse treatment

You can also plan for your future medical care by making an advance decision to refuse treatment. This is sometimes called a 'living will'.

An advance decision sets out in advance your decision about any medical treatments you don't want to receive in certain situations. For example you may decide not to have a blood transfusion in any circumstances, or that you don't want to be resuscitated if you have a heart attack.

5

If you live in England and Wales and have made an advance decision to refuse a certain treatment, health professionals must follow it when you are unable to make the decision yourself. For this to happen, the advance decision must meet certain legal requirements.



For more information, see factsheet 463
Advance decisions and advance statements.





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I've made an advance decision and placed it in a sealed envelope.

Person with dementia

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Call our Dementia Support Line on **0333 150 3456**

The law is different in Northern Ireland, but it is possible to make an advance decision. It may also be called an 'advance directive' or a 'living will'. You do not need to use a particular form to make an advance decision in Northern Ireland, but you should include your personal details and details of the advance decisions you wish to make. It should be signed and dated by you. If in doubt speak to a solicitor.

Telling people about your advance decision

You may want to speak to your GP about making an advance decision. If you make one, keep it in a safe place. Make sure the people close to you know that you've made it and where it is.

5

It is important to make several copies of your advance decision so you can give them to any medical professionals that may be involved in your care. An advance decision will be useless if no one else knows about it.

You should give a copy to the following people:

- your GP or doctor
- your hospital team
- a relative or friend you can trust
- your attorney under a Lasting power of attorney for health and welfare, or an Enduring power of attorney.



Advance statement

An advance statement is different from an advance decision to refuse treatment (see pages 16-18). It is an expression of your wishes and preferences that can help others make decisions for you in the future if you can't make them yourself. It is not treated as a legally binding decision made by you. It can cover a much wider range of things than an advance decision such as:

- your favourite foods
- your hobbies and interests
- your favourite music
- your preferences about where you'd like to live in the future and how you want to be cared for
- your religious, spiritual or ethical views
- your political beliefs.

This information will help people understand your likes and dislikes, personal values and beliefs.

You can also cover more difficult topics in your advance statement. These may include whether you'd prefer to die at home or in a hospital or how you balance quality of life against length of life.



Although advance statements are not legally binding, if someone makes a decision for you in the future, they should use your advance statement to help them reach their decision. There has to be a good reason for them to make a decision that goes against your advance statement.

You can make an advance statement at any time and in any form. Some people find it useful to make an audio or video recording of themselves expressing their wishes. You may feel that you can do this even if you find it hard to talk to those close to you. This is still useful to do but it is important to note that, under the Mental Capacity Act 2005, any written statement you make while you have mental capacity is particularly important when it comes to making decisions on your behalf in the future. This is why it can be a good idea to write an advance statement as soon as you can after being diagnosed.

6

If you decide to complete an advance statement, you can do so on your own but it may help to discuss it with family members and friends who you trust. Whatever you decide, you should also tell all the people involved in your care where the statement is kept so that they know about it.

It is possible to make an advance statement in England, Wales and Northern Ireland.



Advance statement form

There is a suggested advance statement form at the end of this booklet. Turn to page 36 to access this and instructions on how to use it.

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Talking enables you to tell loved ones how you're feeling and they in turn should also feel able to talk. If you don't talk, how do people know how to help you?

Person with dementia

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6





Future care and end of life planning

Dementia gets worse over time so it can be helpful to think about the care and treatment you'd like to receive in the future. This includes at the end of your life. Planning for your future care and treatment is known as 'advance care planning'.

You might not want to think or talk about how you want to be cared for in the future, particularly at the end of your life. Many people find it difficult to talk about this – including health and social care professionals. But having these conversations now or even recording your wishes in some way can help your family, friends and the professionals involved in your care to know what you want if you can't decide that for yourself.

There are different ways to plan ahead for your care and treatment, such as:

- making an LPA for health and welfare (in England and Wales) – see pages 9-11
- making an advance decision – see pages 16-18
- making an advance statement – see pages 19-21.

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You can also discuss your plan for your future care and treatment with health and social care professionals. They can record your wants and wishes in your medical records and/or your care plan. They can also make a note if you have made an LPA, an advance statement or an advance decision.

Some doctors may encourage you to discuss this. They might suggest that you complete a form which records your preferences for the future. Different forms are used in different places and some hospitals have their own. Sometimes you might be offered a 'Preferred Priorities of Care' form which is a type of advance statement. The 'ReSPECT' form is also becoming more common for use in an emergency. This is completed by you and a doctor together. How you choose to plan for your future care is up to you.

7 You can do one, some or all of these things. Some people decide not to do any of them. If that's your choice, thinking about these things can still be helpful and you can still share your wants for the future. Think about having a conversation with your family or close friends and tell them what you want to happen so they can try to make sure your wishes are respected.



There may come a time in the future when you don't have the mental capacity to decide about your care or treatment. If you have not appointed a health and welfare LPA attorney to decide for you, or if you haven't made an advance decision that applies, health or social care professionals will normally decide what happens based on what is in your 'best interests'. They would still need to take account of your wishes and feelings, including anything in your advance statement if you have made one, but the decision would be theirs.



For more information about making a decision in a person's best interests, see factsheet 460 **Mental Capacity Act 2005**.

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If you are in a place that you want to tell someone your wishes when you come to the end of your life, do so, or at least write it down while you can.

Person with dementia

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Call our Dementia Support Line on **0333 150 3456**

Wills

If you make a Lasting or Enduring power of attorney, it will automatically come to an end when you die. If you want to plan what will happen to the things you own after you die, you need to make a will.

A will is a legal document that says who should receive the things you own when you die – such as your property, savings or valuables. If you already have a will, you may want to update it. You need to have mental capacity to make or update a will.

You don't have to ask a solicitor to help you make or update a will but it is usually a good idea. It can be easy to make a mistake if you do it yourself. Also, if someone challenges your will after you die on the basis you didn't have mental capacity to make or change it, the solicitor may have notes that can show you did.



If you don't make a will, the 'intestacy rules' will operate after you die. The intestacy rules are legal rules that will decide what will happen to the things you own. Under these rules your property and other things you own may go to your spouse or civil partner or certain close relatives, or it may be shared between them. This may not be what you want, so it's a good idea to make a will if you want to make sure your wishes are followed. It's particularly important to make a will if you have a partner who you want to inherit your things but you are not married or in a civil partnership.

We can put people in touch with a solicitor through our Will to Remember scheme – for details go to alzheimers.org.uk/willtoremember

You might own some things jointly with someone else, for example a property or a bank account with your partner. The other person may automatically become the owner of the whole property or account when you die. This will happen whatever your will or the intestacy rules say. You should get advice from a solicitor about this and what to do if you don't want that to happen. The way that joint property is owned can be changed so that it does not go automatically to the other joint owner.



Funeral planning

Some people plan their funeral in advance. You may choose to do this so you can plan the funeral you want. Planning your own funeral can be a difficult experience, so make sure to do this at a time that feels right for you. You might want to ask close relatives, friends or someone else who knows you to help you plan your funeral.

Though a funeral can be difficult for those who attend, it can also be an opportunity for people to remember and celebrate the person who has died and the memories they have shared together.

Because of this, you may want to plan your funeral in a way that's unique to you. You could follow a particular religious ceremony or make a request to include things that are important to you, such as your favourite songs, flowers, or a special reading or poem.

You don't have to plan your funeral if you would prefer not to. Many people decide not to do this. If you do decide you want to plan some parts or all of your funeral, it can make it easier for your friends and family to carry out your wishes on the day. Funeral directors can give you more information about planning a funeral.

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My will is done and my funeral arranged and paid for so I don't have to worry about those things... long ago I decided I would not look back at what I can't do, but forward to what I can!

Person with dementia

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9



Call our Dementia Support Line on **0333 150 3456**

Organ donation

You may wish to think about whether you want to donate your organs when you die. The law in England, Wales and Northern Ireland is that you need to opt out of being an organ donor if you don't want to donate your organs. If you have not recorded an organ donation decision, the starting position is that donation will go ahead. A specialist nurse will also speak to your family about organ donation. Your organs will not be donated if your family objects to it. If you have not recorded a decision and there is also no one close to you available to speak to, organ donation will not go ahead.

If you want to opt out, you can contact the NHS Organ Donor Register. See 'Other useful organisations' on pages 34-35.

You can also register to confirm specifically that you do wish to donate. If you do this, it is important to talk to your family so that they know and can support your wishes.

Making the decision to donate your organs or not is a personal choice, and there is no right or wrong decision to make.

10



Donating your brain for dementia research

You can also consider donating your brain to help with dementia research. To find out more go to **alzheimers.org.uk/research/our-research**



Checklist

Below is a list of things you may want to do after you've read this booklet.

- Organise any paperwork you have about your finances and personal affairs. This will help you access it easily. It will also help anyone who is looking after your affairs in the future.
- Make a Lasting power of attorney (or an Enduring power of attorney in Northern Ireland) so that someone you trust can make decisions on your behalf if you're not able to. See pages 9-14 of this booklet. For more information, see factsheet 472 **Lasting power of attorney** or factsheet NI472 **Enduring power of attorney and controllership**. If you are in England or Wales, you can call Alzheimer's Society on **0333 150 3456** for extra support.
- Consider creating an advance decision to refuse treatment (see pages 16-18). You may find it helpful to speak to your GP about creating one.
- Read the suggested advance statement form on pages 36-44. Fill in the parts you want to and add more pages if you need. You can also download the form at **[alzheimers.org.uk/publications-list](https://www.alzheimers.org.uk/publications-list)**
Let your family and friends know where your advance statement is kept, so that they are aware of your wishes.



- Think about talking to your GP or another medical professional about what treatment you would want in the future if you are unable to decide about it (see pages 16-18).
- Make or update your will (see pages 26-27).
- Consider planning your funeral or tell the people closest to you about your wishes (see pages 28-29).
- Think about whether you want to be an organ donor and, if not, consider opting out (see pages 30-31).

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Let loved ones and friends know your desires and wishes for when you progress, how you want to be cared for, and generally tending to those final important matters. That proved to be highly beneficial to my loved ones. It also gave me peace of mind. Less worry meant less stress.

Person with dementia

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Other useful organisations

The Association of Lifetime Lawyers

020 8234 6186

www.sfe.legal

The Association of Lifetime Lawyers is a national association of solicitors, barristers and legal executives who are committed to providing legal advice for older people, their families and carers.

NHS Organ Donor Register

0300 123 23 23

enquiries@nhsbt.nhs.uk

www.organdonation.nhs.uk

The NHS Organ Donor Register includes a record of people who do not want to donate their organs.

**Office of Care and Protection (OCP)
in Northern Ireland**

0300 200 7812

epa@courtsni.gov.uk (for enquiries about Enduring
power of attorney)

<https://www.justice-ni.gov.uk/topics/office-care-and-protection-patients-section>

The OCP is part of the High Court of Justice in Northern Ireland. It deals with the registration of Enduring powers of attorney and the appointment of controllers.

Office of the Public Guardian (OPG)

0300 456 0300

customerservices@publicguardian.gov.uk

www.gov.uk/opg

The OPG supports and promotes decision making for people who lack capacity or who would like to plan for their future within the framework of the Mental Capacity Act 2005.

Template advance statement

Use this form to set out things that are important to you. It won't be legally binding but can be used to guide people who may be making decisions about your care or medical treatment at a time when you are unable to make those decisions yourself.

Only fill in the sections you want to. You can leave the rest. You can also add other preferences or wishes you have on extra pages if needed. You can always make changes to your advance statement in the future.

Remember that there may come a time in the future when you find it difficult to express your wishes. A statement that you make while you have the mental capacity to make it will be stronger.

It may be helpful to complete this form with a friend or family member you trust. Tell those close to you that you have made this statement and where you will keep it.





Who I am

Name and address

Name

Address

Telephone

Email

Details of the attorney/s in any Lasting or Enduring power of attorney you have made (if you have more than two attorneys, add their details to an extra page)

Name

Address

Telephone

Name

Address

Telephone





About me

Use the next three pages to write a bit about yourself and what makes you who you are. This will help those around you make you comfortable and happy in the future. You can include anything you want in this list. Here are some suggestions to get you started:

- people who are important to you
- your pets
- your religious, spiritual or political beliefs and values
- your sexuality
- your gender identity
- important things from your background or culture
- any hobbies or activities you like to do
- how you like to look
- which routines you follow
- your favourite foods and drinks, or food and drink you don't like
- any dietary requirements and allergies
- things you dislike or make you unhappy or angry
- things that frighten you.





My health and care

Details of my GP

Name

Address

Telephone

Conditions that affect me and medication I am taking

List any medical conditions you have and what medication you take for them.

People I would like involved in discussions about my future care and medical treatment

List the names of anyone you would like to be consulted here.



Where I would prefer to live

Explain where you would prefer to live and be cared for if you cannot live independently. For example, you may want to stay in your own home for as long as possible, or you may prefer living with other people in sheltered accommodation or a care home.

How I show I'm unwell

If you have difficulty communicating in the future, it may help the person caring for you to know signs to look out for.

If I am unwell, what helps and what I wouldn't want

List any type of care or medication that is helpful for you if you are unwell and what treatments you would not want.

Please note: this statement is not legally binding. To refuse treatments in a legally binding way, you should consider making an advance decision to refuse treatment (see '**Advance decision to refuse treatment**' on pages 16-18).



My care and treatment preferences

If you have wishes about how you are cared for (for example whether you would prefer to be cared for by a man or a woman) write them here.

Treatment priorities

You can explain here if you would accept treatments that make you comfortable but shorten your life. Or you might say that you prioritise the length of your life over physical comfort.

What I want to happen if I am very unwell and at the end of my life

Explain where you would like to be cared for at the end of your life and who you would want to be there. Say if there is anything that would be helpful for you such as particular music or prayers.



Signed

on (date)

Reviewed and signed

on (date)

Reviewed and signed

on (date)

If you would like to create a similar document to help professionals support you day to day, you can use our free tool called **This is me**[®]. In this booklet, you can include information about your cultural and family background, as well as your preferences and routines. **This is me**[®] can be used alongside care plans and you can fill it out as well as this advance statement. An advance statement contains more about care planning for the future.



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Reviewed by: Sarah Greene, Solicitor, Fieldings Porter, and member of Solicitors for the Elderly and Society of Trust and Estate Practitioners and by Tim Devlin, King and Gowdy Solicitors, Belfast.

This booklet has been reviewed by people affected by dementia.

To give feedback on this booklet, or for a list of sources, please contact **publications@alzheimers.org.uk**

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Practical arrangements after diagnosis**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804**



**Alzheimer's
Society**

It will take a society to beat dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

Booklet code 1510