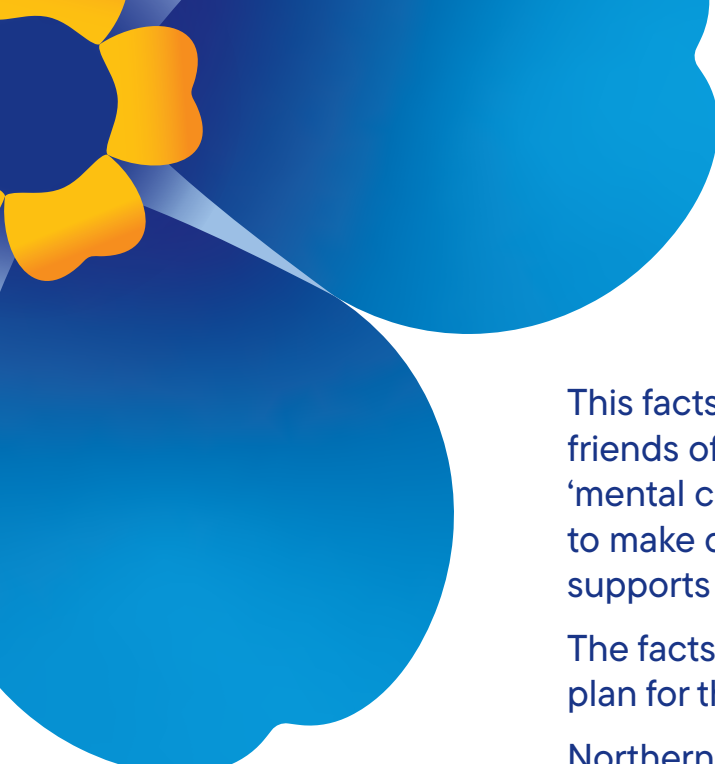


Mental Capacity Act 2005



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for carers, family members and friends of a person with dementia. It explains what ‘mental capacity’ is, how it affects a person’s ability to make decisions and how the Mental Capacity Act supports them.

The factsheet also looks at how the Act can help plan for the future.

Northern Ireland has different laws around mental capacity. People who live in Northern Ireland can find relevant information in factsheet NI472, **Enduring power of attorney and controllership.**

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1 Mental capacity and dementia

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When a person has mental capacity, it means they are able to make a specific decision at a specific time. People who can't do this are said to 'lack capacity' to make that decision. This might be due to having an injury, a learning disability, a mental illness or a condition that affects the brain – such as dementia.

To have mental capacity to make a specific decision, a person must be able to:

- **understand the information** that is relevant to the decision they want to make
- **keep the information in their mind** long enough to make the decision
- **weigh up the information** that is available to make the decision
- **communicate their decision in any way**. This can include talking, sign language or simple movements, such as blinking or squeezing a hand.

As their condition progresses, a person with dementia may become unable to make some decisions. When this happens, they are considered to lack the mental capacity to make the decision at that time.

With dementia, mental capacity can change over time. It can also change in both the short term and the long term. For example, there might be days or even times of the day when the person can think more clearly. This means they may have capacity to make a decision at some times but lack capacity at other times.

A person may also have the capacity to make some decisions but not others. For example, a person may be able to decide that they want to go on holiday but not be able to make choices about accommodation options. This is because some decisions involve having to take in more information. This can be harder for the person to process or understand.

Some decisions, such as whether to move into a care home, involve many factors to weigh up. This may also be harder for the person to consider. You should not assume that a person can't make simple decisions, such as what to wear, just because they can't make difficult financial or medical ones.

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2 The Mental Capacity Act and decision-making

The Mental Capacity Act is the law in England and Wales that protects and supports people who lack capacity to make a decision. It also outlines who can and should make decisions for them.

The Mental Capacity Act covers decision-making about a person's property, financial affairs, and health and social care. It also covers everyday decision-making, such as what a person wears, what they eat and their personal care.

It does not cover decisions such as voting, making a will, marriage or divorce. For advice on these decisions, talk to a relevant professional or visit the government website at gov.uk.

The Act can help people with dementia, their carers and professionals to make specific decisions and to plan for the future.

The principles of the Mental Capacity Act

The Mental Capacity Act is based on five key principles or rules, which are mentioned throughout this factsheet. These are:

- 1 A person has the right to make decisions for themselves. You must assume that someone is able to make their own decisions, unless it is shown that they can't do this.
- 2 A person should not be treated as being unable to make a decision unless they have been given all reasonable help and support to make and communicate their own decision.
- 3 A person should not be treated as being unable to make a decision just because other people think they have made a bad decision.
- 4 If a person lacks capacity, any decisions that other people make for them must be in the person's best interests. The Act includes a checklist that people must work through when they are deciding what is in the 'best interests' of someone who lacks capacity. See 'Does the person have the mental capacity to make this decision?' on page 5.
- 5 If a person lacks capacity, the people making the decision for them must consider the option that is the least restrictive to the person's rights and freedoms.

3 Assessing capacity

You must always assume that a person is able to make a decision for themselves. This is until it is proved that they can't. A person's mental capacity may be questioned if there is doubt about whether they can make a particular decision. This could happen if:

- **the person's behaviour or circumstances** are making those around them doubt if the person has capacity to make a particular decision
- **a professional says they have doubts** about the person's ability to make the decision – this could be a social worker or the person's GP
- **the person has previously been unable to make a decision** for themselves.

To work out whether a person has capacity to make a decision, the law says you must do a test. This is often called an assessment. This is to find out if the person has the ability to make the particular decision at the particular time.

Before the person is tested, they should be given as much help as possible to make the decision for themselves. Those who are supporting them to make the decision should find the most helpful way to communicate with the person.

This may mean trying to explain the information to them in a different way. It can also mean helping them to understand the ideas that are involved in making the decision.

It may help to break down information into small chunks. For more information about communicating with a person with dementia, see factsheet 500, **Communicating**.

Not all decisions need to be made immediately. It is sometimes possible to delay a decision until a person has capacity to make it. However, this won't be possible for every decision.

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Who can assess capacity?

In general, whoever is with the person when they are making a decision will assess their capacity. However, this will differ depending on the decision that needs to be made:

- **Everyday decisions** – for example, what someone will eat or wear. Whoever is with the person at the time can assess their capacity to make the decision. This is likely to be the person's family member, carer or care worker.
- **More complicated decisions** – for example, where someone will live or decisions about treatment. A professional will assess the person's capacity to make the decision.

How is capacity assessed?

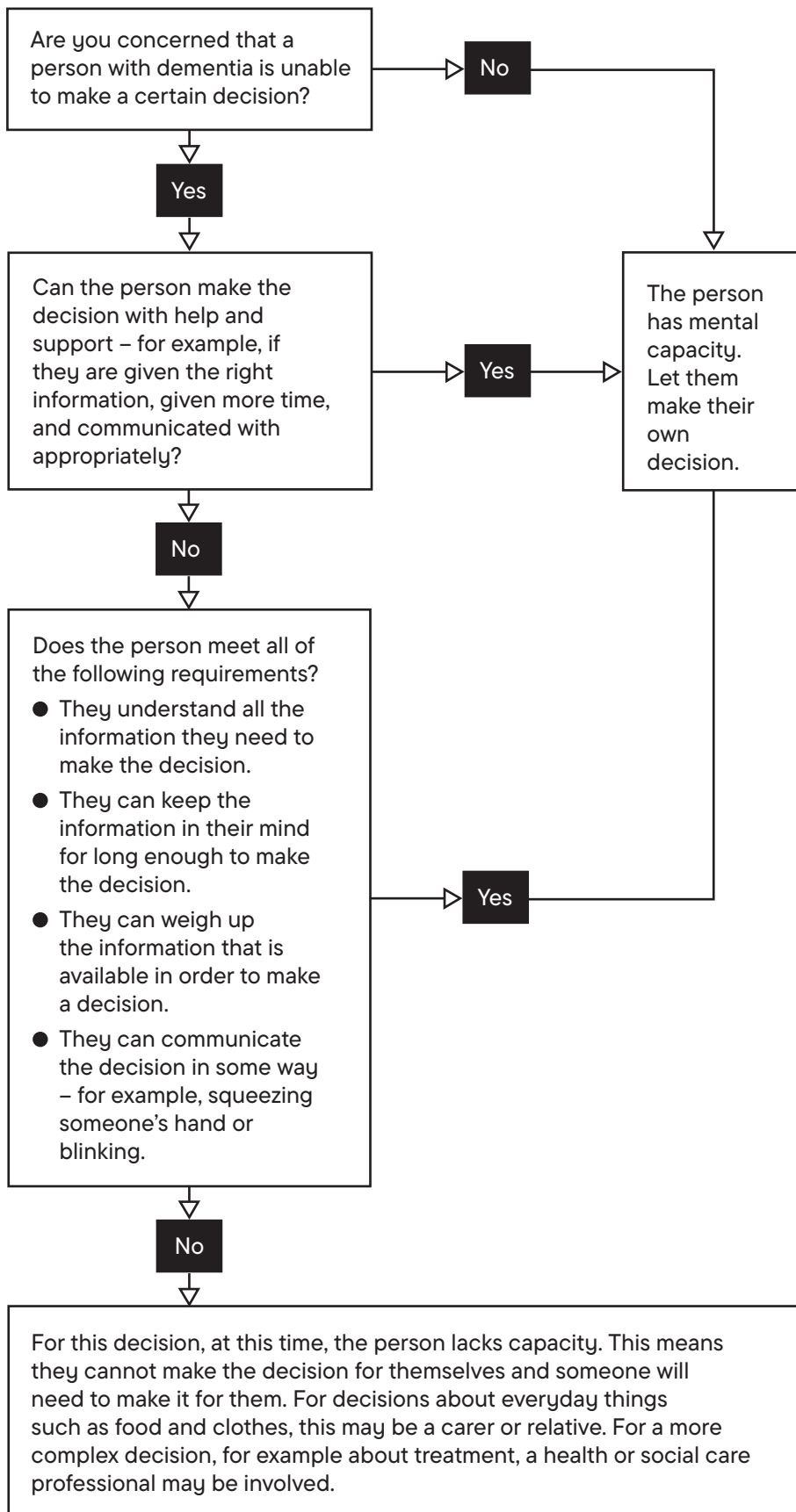
When a person has dementia, it's likely that those around them will need to assess capacity more often as their condition progresses.

The flowchart 'Does the person have the mental capacity to make this decision?' on page 5 will help you decide if a person has the mental capacity to make a specific decision. Before making a decision for the person, family members or carers must believe the person can't make their own decision. In general, family members and carers know the person best. They can often tell when the person is or is not able to make a decision.

Try to use your knowledge of the person to help you decide. You can also ask other people for advice, such as the person's GP, community nurse or social worker.

Does the person have the mental capacity to make this decision?

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Challenges to capacity assessments

The outcome of a capacity assessment is sometimes challenged. This can happen for the following reasons:

- if someone else feels that a person had the mental capacity to make a decision, but they were not allowed to do so
- if someone feels the person did not have the the mental capacity to make a decision, but they were allowed to make one.

The person can challenge a capacity assessment themselves. Or it could be challenged by their family member, friend or even a professional.

If you want to challenge the outcome of a capacity assessment, start by speaking to the person who did the assessment. Ask why they made the decision they did. Explain why you disagree with their assessment of the person's capacity. If this doesn't help, you can ask for the decision to be reviewed. This should be either by the person who first made the assessment or by the organisation involved. This may be social services or a hospital.

If you are still not satisfied, you can make a formal complaint. For example, you may disagree with a GP or a care home manager. If so, the surgery or care home will have its own complaints procedure to follow. Ask them for information about how to make a complaint.

If you challenge a capacity assessment, it could harm your relationship with the person who did the assessment. Therefore, before you challenge it, think about speaking to a local advice agency, a carers' service or a solicitor. If you contact a solicitor, make sure you ask them at the start of your conversation how much they will charge. You can also call our Dementia Support Line on **0333 150 3456**.

If someone challenges a capacity assessment that you have made, try to stay calm. Take your time to explain why you believe the person could or couldn't make the decision for themselves. Carers and family members are not expected to write down each time they have to make a judgement about a person's capacity. They are also not expected to note what their reasons were, especially when they are making decisions every day. However, if you are asked, you should be able to give examples to show why you made the decision.

This doesn't happen often. Most family members and carers will never be challenged about the capacity assessments they make. But it is something you should think about when you are judging whether the person has capacity to make a decision. The law says you must have a 'reasonable belief' that the person lacks capacity, so you would need to show that you had this belief.

If you are assessing whether a person with dementia has capacity to make a major decision, you might want to talk to a professional. This could be a solicitor or a health or social care professional. Note that certain professionals may charge for advice. Major decisions could include the person wanting to change their will or sell their house. It could also include decisions about their care and treatment.

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4 Making decisions

A capacity assessment may show that a person lacks the capacity to make a certain decision at that time. If this is the case, the decision needs to be made for them.

Who makes the decision?

The type of decision that needs to be made will affect who should make the decision. If it is an everyday decision, it's likely that someone who is there at the time can make the decision for the person with dementia. If it is a more complicated decision, such as finances, care or treatment, you may have to speak to the person's attorney or deputy (if they have one). You could also talk to a professional who is involved in their care.

For more information see 'Lasting powers of attorney' on page 11 and section 6 'If someone hasn't planned ahead: Deputyship' on page 14.

Examples of types of decisions and who can make these for a person with dementia are shown below.

- **Everyday decisions about washing, dressing, eating or activities.** Whoever is with the person at the time can make these decisions, such as a carer, family member or care worker.
- **Complicated decisions about finances or property.** If the person has an attorney or deputy for property and financial affairs, they will make these decisions.
- **Decisions about where the person will live and receive care.** If the person has an attorney or deputy for health and welfare, they can make the decision. If not, a professional such as a social worker or doctor will make the decision.
- **Decisions about life-sustaining treatment.** If the person has appointed an attorney for health and welfare and given them this power, the attorney may be able to make the decision. If the attorney can't make the decision, it will be made by an appropriate doctor or consultant.
- **Decisions when there isn't someone who knows the person with dementia well.** The local authority (council) may appoint an independent mental capacity advocate (IMCA) to speak on the person's behalf. This will happen when a major decision needs to be made, such as whether the person should move to a care home or have serious medical treatment. An IMCA is also sometimes involved if there is conflict between family members.

Making decisions in the person's best interests

When a decision is made for a person who is not able to make that decision, it must always be made in their 'best interests'. This makes sure that the person's rights are respected, and that the decision is the best one for them.

A decision should never be made in the best interests of anyone other than the person themselves. For example, a decision should never be made to make things easier for a carer or professionals who are caring for the person.

A number of things should be considered for a decision to be made in a person's best interests. These are listed in the best interests checklist on page 10.

Consultation rights and best interests decisions

The person with dementia has a right to be involved in decisions that are made about them. This is unless that's inappropriate – for example, if someone refuses to be consulted. This is very important. If someone can't make the decision themselves, this does not mean that they won't have preferences and feelings about what they would like to happen.

Family members, friends and carers also have a right to be consulted and involved in the decision, where appropriate. This is important and can be helpful because they often know the person best. They can say what they think is in the person's best interests, as well as what the person's preferences and views are.

There may be a 'best interests meeting' if the decision is more complicated. For example, this can be decisions about where the person will live. A best interests meeting isn't always needed. However, when it is, it can be a good way to consider all the different issues involved in the decision. This includes the views of the person and their family members. Sometimes, family members or the person's representatives will be invited to the best interests meeting. If family members disagree, the views from both sides of the argument should be taken into account.

At other times, family members won't be invited to the best interests meeting. Often, the person themselves is not invited to attend. If the person and their family are not invited, their views should still be considered during the meeting. How this is done will depend on the situation. For example, they could offer their views in writing or through someone else, such as an IMCA. Or the person with dementia or their family could meet with a professional before the meeting to share their views.

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Best interests checklist

- Consider whether the person will have capacity later and whether the decision can be put off until then. This is crucial because a person with dementia may have good and bad days. They may be able to make the decision on another day.
- Encourage and support the person with dementia to take part in making the decision and to share their views, where possible.
- Consider the person's past, present and future wishes and feelings.
- Take into account other people's views, such as carers, friends, family members and any attorney or deputy the person may have.
- Note that decisions can't simply be based on the person's age, behaviour or the fact they have dementia (or any other condition).
- Take into account all the relevant circumstances when making a decision. For example, think about what things the person would have considered if they'd been able to make the decision themselves.
- If the decision involves life-sustaining treatment, there are other issues that need considering. For example, check whether the person has made an advance decision. See 'Advance decisions' on page 12. All possible treatment options need to be considered. No decision can be motivated by a wish to end a person's life. If there is any doubt about the person's best interests, the case should be referred to the Court of Protection. It will make the decision. See 'Other useful organisations' on page 15.

5 Planning ahead

The Mental Capacity Act sets out a number of ways for a person to plan ahead in case they can't make decisions for themselves in the future. This means the person can make sure that what they want to happen will happen. This is even if they can't decide or communicate their views in the future. This section describes ways that people can put plans for the future in place, if they want to.

Lasting powers of attorney

A Lasting power of attorney (LPA) enables a person to appoint someone they trust to make decisions for them in the future. This is if they can't make a certain decision or decisions for themselves. The person (or people) they appoint will become their 'attorney'. To make an LPA, a person needs to fill in a specific application form. This form needs to be signed and witnessed by various people before it is registered with the Office of the Public Guardian (OPG). See 'Other useful organisations' on page 15. An LPA must be registered before it can be used.

There are two types of LPA. They each relate to different decisions. A person can have both types of LPA, but to do this they will need to complete both forms. The two types of LPA are:

- **LPA for property and financial affairs.** This gives the attorney or attorneys the power to make decisions about things like selling the person's house or managing their bank account.
- **LPA for health and welfare.** This gives the attorney or attorneys the power to make decisions about the person's health and personal welfare. These include day-to-day care, medical treatment or decisions about where they might live, such as a care home. This is so that they can receive care and support.

For more information on how to make an LPA, see factsheet 472, **Lasting power of attorney.**

You may also hear about Enduring powers of attorney (EPA). These were used before LPAs were introduced under the Mental Capacity Act. If an EPA was made properly and signed before October 2007, it can still be registered and used. An EPA only allows the attorney to make decisions about a person's finances and property. It does not cover health and welfare decisions.

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If you don't have access to the internet or feel able to complete the LPA forms on a computer, Alzheimer's Society offers a digital assistance service. We can help you to create an LPA for the person using the Office of the Public Guardian's online tool. For more information on this service, call our Dementia Support Line on **0333 150 3456**. The service doesn't provide legal advice.

Advance decisions

The Mental Capacity Act also enables someone to create an advance decision to refuse treatment. This allows them to state the types of treatment they don't want to have. This is if they don't have the mental capacity to decide this for themselves in the future. It may include refusing life-sustaining treatment.

A valid advance decision is legally binding, which means health professionals must follow it. The treatment and circumstances set out in the advance decision must apply to the specific situation the person is in.

To be valid, an advance decision must be made in writing. It must also be signed and witnessed. It can help if the person has a conversation with their GP before they make an advance decision. This is to make sure that the advance decision covers what the person wants it to.

Advance statements

Another way that people can plan ahead is by creating an advance statement. This is where they can set out their wishes and preferences for the future, including both what they want and what they don't want to happen. The statement could include:

- their preferences about their care
- where they will live
- what they like or don't like to eat
- daytime activities they enjoy
- who they do and don't want to visit them.

Advance statements can be made verbally or in writing. They are not legally binding. If someone is making a decision for a person who has made an advance statement, they must take the statement into account when they make the decision.

For more information about advance statements and advance decisions, see booklet 1510, **Planning ahead** and factsheet 463, **Advance decisions and advance statements**.

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6 If someone hasn't planned ahead: Deputyship

A person with dementia may lose the ability to make some decisions. If they haven't made an LPA or EPA, it can become difficult for those who are trying to help them. This is especially true for financial decisions. Only someone who has a legal power (such as an LPA, EPA or deputyship) can completely manage another person's finances.

If you are caring for a person who hasn't made an LPA or EPA, you will need to apply to the Court of Protection to become their deputy. This is to be able to manage their finances for them. Do note that it can take several months for this to be set up. The process is also more expensive, with a higher cost for applying and ongoing fees after you've been appointed.

It is also possible to become a person's deputy for health and welfare decisions. You will need to show the Court that the person needs to have a deputy. You can do this by showing that ongoing decisions need to be made about the person's welfare that only a deputy can make.

The Court doesn't appoint as many deputies for health and welfare. This is because professionals and family members can sometimes work together to make decisions in the person's best interests. So a deputyship is not always needed.

For more information about deputyship and how to apply for it, see factsheet 530, **Deputyship**.

Other useful organisations

The Association of Lifetime Lawyers
020 8234 6186 (9am–5pm Monday–Friday)
www.lifetimelawyers.org.uk

The Association of Lifetime Lawyers (formerly Solicitors for the Elderly) is an independent, national organisation of lawyers who provide legal advice to older people. They can also help you to find a solicitor.

Court of Protection
0300 456 4600
courtofprotectionenquiries@justice.gov.uk
www.gov.uk/court-of-protection

The Court of Protection helps people who have difficulty making their own decisions. It either makes a decision for the person or appoints someone else to do so.

Office of the Public Guardian
0300 456 0300 (customer services, 9am–5pm Monday, Tuesday, Thursday, Friday; 10am–5pm Wednesday)
customerservices@publicguardian.gov.uk
www.gov.uk/opg

The Office of the Public Guardian supports and promotes decision-making for people in England and Wales who lack capacity or who would like to plan for their future within the framework of the Mental Capacity Act 2005. The Office of the Public Guardian has a range of useful information on the GOV.UK website, including the Mental Capacity Act Code of Practice.

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Reviewed by: Tim Farmer, CEO, TSF Consultants and Irene Chenery, Consultant, Harrison Drury Solicitors; member of The Association of Lifetime Lawyers

To give feedback on this factsheet, or for a list of sources, please email 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** or visit **alzheimers.org.uk/donate**



Patient Information Forum



Together we are help & hope
for everyone living with dementia

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

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

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