

Accessing and sharing personal information



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



About this booklet

We all share personal information with organisations. This could be to arrange repeat prescriptions, claim benefits or pay bills. Sometimes, you may need to access personal information an organisation holds about you or someone else. This booklet will help you to understand when and how you can do that.

This information is mostly for someone supporting a person with dementia. However, if you need to access personal information about yourself, the advice on page 8 about subject access requests will help you.

The information in this booklet is based on laws that apply in England, Northern Ireland and Wales. Where laws are different across these nations, we explain this.

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1 Accessing information

In this section, you can read about when and how you can access information.

Can you access information on behalf of someone with dementia?

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Use the flowchart on page 3 to understand when you can access or share information about someone with dementia with an organisation.



Do you need to access or share information on behalf of a person with dementia?

NO

YES

Do you have consent from the person?

NO

YES

In some cases, you may not be able to access the person's information. But, you may be able to if you have a valid reason. You may be representing the person in a complaint or applying for NHS continuing healthcare funding.

In this case, give proof of the person's consent, which may be verbal or in writing. This should mean you can access or share information as agreed by the person.

Do you have a legal power, such as power of attorney, deputyship or controllership?

NO

YES

The organisation will only be able to disclose information in limited circumstances. However, you can share information with them, if appropriate.

You can usually share and access information on the person's behalf, using the processes the organisation has in place. For more information see 'Legal powers' on page 11.



Information you might need to access

Medical records

You may need to access the medical records of someone with dementia. This could be to:

- help them manage prescription medicines
- help with decisions about their care and treatment
- make a complaint
- apply for funding, such as NHS continuing healthcare funding.

To access someone's medical records, you need to make a **subject access request** to the relevant organisation. This might be the GP surgery or the hospital where they are receiving treatment. See 'Making a subject access request' on page 8.

You should be able to access someone's medical records if you have the relevant legal power, or the person's consent. If you don't have either of these, you will need to explain why you need access to the information and why it's in the person's best interest.



Care assessments

To access care and support, many people with dementia will have a care assessment. Social services carry out these assessments.

People close to a person with dementia often want to see the results of this assessment. It can be helpful to know what their care needs are and the services that have been suggested or put in place to meet them. In these cases, a subject access request is not always needed, as other laws can give people access.

- In **England**, local authorities must share the assessment with the person with dementia and their carer. They must also give a copy to anyone else the person with dementia asks them to.
- In **Northern Ireland**, local trusts should share the assessment with the person with dementia and their carer.
- In **Wales**, local authorities must share the assessment with the person with dementia, or anyone with a legal power to act on their behalf. If there is no one with legal power, the local authority should give a copy to someone acting in the person's best interests, such as a carer or family member.



If these obligations are not met, you can complain to the local authority or health and social care trust and ask for access.

Alternatively, you can still make a subject access request. Someone who may not have automatic access to this information, such as a family member who is not a carer, may also make a subject access request. The organisation will let you know if they are able to agree to your request. This person also has the right to complain if they feel the request has not been handled correctly.

Care home records

When a person is living in a care home, their family and friends may want to see their care home records. If the person is able to, they can consent to someone else viewing their records.

If they can't consent, anyone with an appropriate legal power should see the records if they need it to carry out their role. This includes:

- an attorney or deputy under an LPA or EPA for health and welfare, who needs to make a decision about the person's care or treatment
- an attorney, deputy or controller with power over a person's finances, who need this information to ensure that they are paying for care that meets the person's needs, or for a financial assessment.



Care homes usually share records without needing a subject access request. However, if the care home does not give you access to the records after you ask, you can make a formal request. See 'Making a subject access request' on page 8.

If you don't have a legal power or consent from the person, you might find it more difficult to access care home records. However, you can still ask and put in a subject access request, if needed.

If you do have a legal power or consent, it's important to explain why you need this information and why it is in the person's best interests.

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How to access information

When someone asks an organisation for personal information, it is known as a **subject access request**. You can make a subject access request for yourself or for someone else. It helps you find out what information an organisation holds and how they are using it.

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You can make a request verbally (for example, over the phone) or in writing. If it's verbal, we recommend that you follow this up in writing, so there is a physical record.

Where to send a subject access request

You should send a subject access request directly to the organisation. It may be a person or department, such as a data controller or a data protection department. If you're not sure who to send it to, ask the organisation. Or send the request to the general address, so they can pass it on to the appropriate person.

Making a subject access request

Many healthcare organisations have their own subject access request forms. Ask your provider if they have one for you to complete.

The Information Commissioner's Office also offer a new service to help you request personal information – **ico.org.uk/for-the-public/make-a-subject-access-request**

You can also create your own subject access request. Make sure you keep a copy of your request and any proof of postage/delivery.



What to include in a subject access request

State what information you want and your reasons for needing it. For example, you might need details on a person's investments because you are managing their finances.

You will also need to include:

- your name and contact details
- the name and contact details for the person whose information you wish to access
- your authority to be requesting information on the person's behalf, for example:
 - you have the person's consent – evidence of this is required, and can be given verbally or in writing
 - another legal basis for your authority, such as, a court order granting you access to this information – you will need to give evidence of any legal basis
 - you have a legal power (see 'Legal powers' on page 11) – you may be asked to show the original or a certified copy of your power, as well as proof of your identity.

To certify a document as a true copy of the original, you need to get it signed and dated by a professional person, like a solicitor. Alternatively, it may have been certified by the person themselves at a time they had mental capacity to do so.



How long does a subject access request take?

The organisation must respond to you within one month. However, in certain circumstances, they can have an extra two months. This can be when the request is complex, or if there is more than one request.

The organisation will usually respond in one of two ways.

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1. They will agree to share the information with you and outline how this will be arranged.
2. They will explain that they have decided not to share the information. If this is the case, they must outline the reasons for their decision. If you disagree with them, you can make a complaint. See 'Making a complaint' on page 19.

Do you need to pay for a subject access request?

The organisation should provide the information free of charge. However, they may charge for extra copies.

They can also charge a fee if they decide the request is 'manifestly unfounded or excessive'. This means that it is clear it is not a reasonable request. However, any fee should be fair for the costs of providing the requested information.



Legal powers

There are many legal powers that mean you can access information on behalf of a person with dementia. Many people believe if they are married to a person, or if they are family or their 'next of kin', they have the right to access and share their information. However, this is not the case. You need to have either the person's consent or legal powers. The legal powers on this page to page 13 are the most common.

1

Lasting powers of attorney (LPA)

A person can appoint someone to make certain decisions for them, if there was to be a time when they were unable to make them in the future.

In **England and Wales**, this is known as a lasting power of attorney (LPA). This power means the person(s) appointed (the 'attorney') can access and share information as needed.

There are two types – one for health and welfare, and one for property and financial affairs.



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



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

Enduring power of attorney (EPA)

Enduring power of attorney (EPA) was replaced by LPA in England and Wales. Although no new EPAs can be made, any made before October 2007 can still be used. However, they only cover financial decisions.

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In **Northern Ireland**, the laws are slightly different and they currently only have EPAs. People can only make an EPA to allow the appointed person(s) known as the ‘attorney(s)’ to make decisions about property and finances – accessing and sharing information as needed.

Deputyship or controllership

There are times when someone has not made an LPA or EPA and they are no longer able to make decisions for themselves. If someone needs to make decisions on their behalf, they can apply to the Court of Protection to become the person’s **deputy**. This includes family, a partner, a close friend, the local authority or a professional.

A deputy has certain decision making powers, which are outlined in the court order they are given. There are two types of deputy – one for property and financial affairs and one for health and welfare.



For more information, see factsheet 530, **Deputyship**.



In Northern Ireland, there is a system of **Controllership**, rather than Deputyship. Controllership means a person can make decisions about someone else's finances and property when they are no longer able to.



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

1

Third party mandates

A **third party mandate** allows someone to give another person permission to access and manage their bank account. This is set up with their bank, normally through an application form. A third party mandate only allows the person to access and manage the account. They will not normally be able to close the account or use an overdraft.

The third party mandate is only valid when the person whose bank account it is has 'mental capacity' to agree to it. Mental capacity means a person's ability to make a decision. So a person needs to be able to decide to have a third party mandate and to choose who does this for them. If they lose mental capacity to consent to this, the power becomes invalid.



For more information on mental capacity, see factsheet 460, **Mental Capacity Act 2005.**



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



2 Sharing information

In this section, you can read about situations where you might need to share information on behalf of someone with dementia.

Information you may need to share

There may be times when you need to share information on behalf of a person with dementia. This could be with an organisation or a health and social care professional, for example.

2

Sharing concerns with someone's doctor

You may want to speak to someone's doctor, but the person is unable to consent and you don't have a legal power. You might want to do this because you are concerned about their memory or health and they won't go to see the doctor.

Other people may tell you that you cannot speak to another person's doctor due to confidentiality. However, this is not correct. You cannot access the person's information, but you can still share information about them with their doctor. The doctor or another healthcare professional should still listen to your concerns. However, it's important to know that the doctor can tell the person you have contacted them and what you discussed.



Helping a person with dementia to report a fault or problem with utilities

You may need to support a person with dementia to fix a problem with their utilities or services. This could include their phone line, internet, gas or electricity. If you have a legal power or the person's consent, you can contact the company on the person's behalf and report the fault.

2

If you don't have a legal power and the person is unable to give their consent, you can still report a fault. Sometimes, companies refuse to speak to other people (third parties) due to confidentiality. While they cannot give you someone else's information, you still have a right to share information with them.

If you have problems sharing information with companies, you can make a complaint – see 'Making a complaint' on page 19.



Cancelling utilities when someone moves into another home

If the person's home is empty when they move into a care home, you will need to let their utility providers know. The person themselves may not be able to do this or may need support.

If you have an appropriate legal power or consent, you can let the utility provider know about the person's move. They should listen to you and act accordingly. They may ask for evidence of the person's consent or legal power. If you have been in contact with the company before and shown them the legal power, you shouldn't need to do this again.

If you don't have a legal power, you can still help the person because the organisation does not need to share information with you. You're simply sharing information with the company.

The organisation may need proof of the move, such as a letter from the care home, or a copy of the care home contract.

2



Being involved in decisions made about a person with dementia

If a person with dementia can't make a decision for themselves, it will need to be made on their behalf.

This may include decisions about:

- care plans
- where they will live to receive their care
- treatments.

2

If you have a legal power, you may be able to make these decisions for the person. If you don't have this, you still have a right to be involved as someone who is important to them.

When any decision is made on behalf of a person with dementia, it must be in their best interests. By law, the decision maker, such as a doctor or social worker must consult those closest to the person. This includes carers, family members and friends, who have a right to be involved in decisions made on behalf of the person.

Anyone close to the person has a right to share information about what they think the person would want and what they think is best for them. However, it doesn't include a right to access information, or make the decision.



3 Making a complaint

There may be times when an organisation doesn't allow you to access or share information on behalf of someone. If you feel that the organisation has acted wrongly, you should complain directly to the organisation. Most organisations have a complaints process for you to follow.

You might do this if you have proven you have a legal power or the person's consent, but the organisation won't let you access or share information.

If you are not happy with the response, you can report your concern to the Information Commissioner's Office (ICO) – see 'Other useful organisations' on page 21.

3



Other useful organisations

Citizens Advice

0800 144 8848 (for England, 9am–5pm Monday–Friday)

0800 702 2020 (for Wales)

www.citizensadvice.org.uk

Citizens Advice offers free advice on resolving problems with debt, benefits, employment, housing and discrimination.

Financial Ombudsman Service

0800 023 4567 (helpline, 8am–5pm Monday–Friday,
9am–1pm Saturday)

complaint.info@financial-ombudsman.org.uk

www.financial-ombudsman.org.uk

The Financial Ombudsman Service is the UK's official expert in sorting out problems with banks, insurance, PPI, loans, mortgages, pensions and other money and financial complaints.



Information Commissioner's Office (ICO)

England

0303 123 1113 (helpline, 9am–5pm Monday–Friday)

www.ico.org.uk

Wales

0330 414 6421

wales@ico.org.uk

www.ico.org.uk/about-the-ico/who-we-are/wales-office

Northern Ireland

0303 123 1114

ni@ico.org.uk

www.ico.org.uk/about-the-ico/who-we-are/northern-ireland-office

The ICO is the UK's independent body set up to uphold information rights.

Local Government and Social Care Ombudsman

0300 061 0614 (10am–1pm Monday–Friday)

www.lgo.org.uk

The Local Government and Social Care Ombudsman is the final stage for complaints about councils and some other organisations providing local public services, as well as care homes and home care providers.



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

Northern Ireland Public Services Ombudsman

0800 34 34 24 (9am–5pm Monday–Friday)

nipso@nipso.org.uk

nipso.org.uk/nipso

The Northern Ireland Public Services Ombudsman investigates complaints where local resolution has not been possible.

Office of Care and Protection (for Northern Ireland)

0300 200 7812 (9am–1pm Monday–Thursday)

ocp@courtsni.gov.uk

[www.justice-ni.gov.uk/topics/courts-and-tribunals/
office-care-and-protection-patients-section](http://www.justice-ni.gov.uk/topics/courts-and-tribunals/office-care-and-protection-patients-section)

The Office of Care and Protection is part of the family division of the high court in Northern Ireland, and is the administration office that deals with the registration of enduring powers of attorney and the appointment of controllers.

Office of the Public Guardian (OPG)

0300 456 0300 (9am–5pm Monday, Tuesday, Thursday, Friday, 10am–5pm Wednesday)

customerservices@publicguardian.gov.uk

www.publicguardian.gov.uk

The OPG protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finances.



Parliamentary and Health Service Ombudsman (England)

0345 015 4033 (helpline, 8.30am–5pm Monday–Thursday,
8.30am–12pm Friday)

<https://www.ombudsman.org.uk>

The Parliamentary and Health Service Ombudsman makes final decisions on complaints that have not been resolved by the NHS in England.

Public Services Ombudsman for Wales

0300 790 0203 (10am–12.30pm, 1.30pm–4pm
Monday–Friday)

ask@ombudsman.wales

www.ombudsman.wales

The Public Services Ombudsman for Wales is an independent body whose role is to investigate and consider complaints where they have not been resolved locally.

Association of Lifetime Lawyers

020 8234 6186

<https://www.lifetimelawyers.org.uk>

The Association of Lifetime Lawyers is a specialist group of lawyers who support older and vulnerable people.





Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: The Office of the Public Guardian (OPG),
Lisa Moore, Information Governance Manager

It has also 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**

This booklet can be downloaded from our website at
alzheimers.org.uk/publications

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Last reviewed: June 2024
Next review due: June 2027

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.

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**



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Society**

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

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

Code 882