



Accessing and sharing information on behalf of a person with dementia





About this booklet

We all share personal information with organisations – for example, to arrange repeat prescriptions, claim benefits or pay bills. If you're supporting someone with dementia, there may be times when you need to access information on their behalf.

It can be difficult to know when or how you can access or share information on behalf of a person with dementia. This booklet will help you to understand when you may be able to or have a right to do this. It also tells you how to complain if you believe you were wrongly denied access to someone's information.

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

If you're caring for or supporting someone with dementia, you may find it helpful to look at other Alzheimer's Society resources. These contain information and practical advice on a wide range of topics and some of these are referenced in this booklet. To access them, you can:



go to alzheimers.org.uk/publications



call 0300 303 5933



or email publications@alzheimers.org.uk



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1



Accessing information

There are a number of different ways you may be able to access information on behalf of a person with dementia. In this section you can read more about how to do this, including advice on accessing specific types of information such as medical records.

Can you access information on behalf of someone with dementia?

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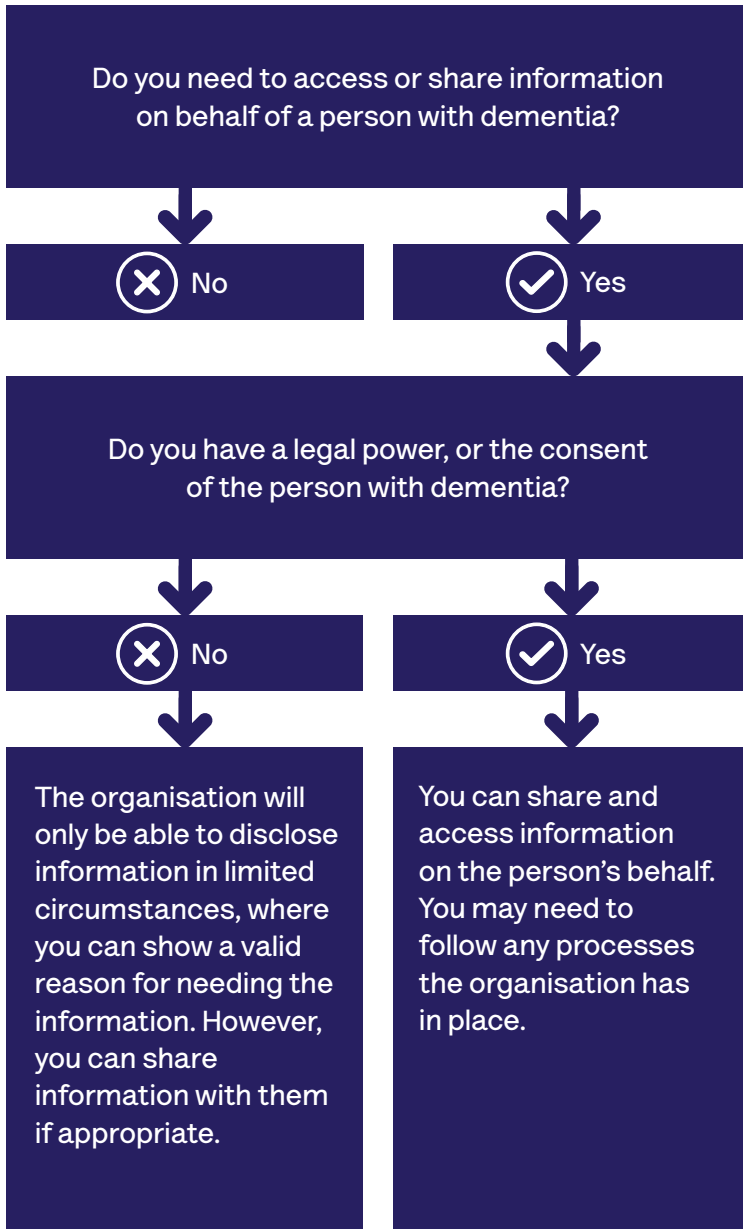
You can use the flowchart opposite to help you understand when you can access or share information with an organisation on behalf of a person with dementia. There is more information in the booklet about these different situations as well as terms in the flowchart such as ‘legal power’.

The flowchart shows that one of the following situations is likely to apply to you:

- **You have a legal power** – if this is the case, you can access and share information where this is allowed under the power you have. You may need to show either the original or certified copy of the power and ID if requested. For more information see ‘**Legal powers**’ on page 8.
- **You have no legal power, but the person has given consent** – in this case, provide the organisation with the person’s consent (which they may give verbally or in writing). This should mean you can access or share information as agreed by the person with dementia.
- **The person with dementia is unable to consent and you have no legal power** – whether you can access or share information will depend on the situation. In some cases you may not be able to access the person’s information. However, if you have a valid reason for needing to, such as representing the person in a complaint about care or an application for NHS continuing healthcare funding, you may be able to.

If you need to, you can share information with organisations even when you cannot access the person’s information. For more information see ‘**Sharing information**’ on page 19.





Legal powers

1

There are many legal powers that mean you can access information on behalf of a person with dementia. Many people believe that because of their relationship to the person (for instance, because they are married, a family member or their 'next of kin') they have an automatic right to access and share their relative's information. However, this is not the case – either the person's consent or legal powers are needed. The following powers are the most common.

- **Lasting powers of attorney (LPA)** – this means a person (in England and Wales) can appoint someone to make certain decisions for them if they are unable to make them in the future. There are two types – one for health and welfare, and one for property and financial affairs. This power means the person appointed (the 'attorney') can access and share information as needed for their role.



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

**'The care home says I can't have the
notes as I don't have a health and
welfare Lasting power of attorney.'**

Carer for a person living with dementia

- **Enduring power of attorney (EPA)** – before October 2007 someone could make an Enduring power of attorney, and those made before this date can still be used. This is similar to an LPA but only allows an attorney to make decisions regarding property and finances.

In Northern Ireland the laws are slightly different to England and Wales. People can only make an EPA to allow someone to make decisions about property and financial matters – accessing and sharing information as they need to.

- **Deputyship or controllership** – there are times when someone has not made an LPA or EPA and are no longer able to make decisions for themselves. If someone needs to make decisions on their behalf – such as a family member, partner, close friend, the local authority or a professional, they can apply to the Court of Protection to become the person's deputy. A deputy is granted 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 the person that applies can manage and make decisions relating to someone else's finances and property when they can no longer do this for themselves.



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



For more help and advice call Dementia
Connect support line on **0333 150 3456**



- **Third party mandates** – these mean a person can give someone else permission to access and manage their bank account. It is set up with the person's bank, normally through an application form. This 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 in this case, someone needs to be able to make the decision 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.

'How am I supposed to appeal a decision about continuing healthcare funding if I don't have the information I need?'

Carer for a person living with dementia

Requesting information: Subject access requests

1

When someone requests their information from an organisation it is known as a subject access request. A person can make one of these to find out what data (information) is held about them and how it is used. It can also be done on behalf of someone else.

A subject access request can be made verbally or in writing. If it's made verbally, it is recommended that this is followed up in writing so that there is a physical record.

To make a subject access request (so that you can access someone else's data) you need to:

- 1. Find out where to send your request** – this will be direct to the organisation, but they may have a named person or department that handles these requests – for example some organisations have 'data controllers' or a data protection department. If you're not sure who to send it to, you can ask the organisation or send the request direct to them so that they can pass it onto the appropriate person or department.
- 2. Make your request** – state clearly what data you want and, if appropriate, your reasons for needing the person's information. For example, you might need details on their investments because you are now managing their finances as their attorney.



Within your request you will also need to include:

- your name and contact details
 - the name and contact details for the person whose data you wish to access
 - your authority to be requesting information on the person's behalf – for example:
 - you have a legal power (see '**Legal powers**' on page 8)
 - you will probably be asked to show the original or a certified copy of your power and may be asked for proof of your identity
 - you have the person's consent – evidence of this is required, and can be given verbally (for example over the phone), or in writing
 - another legal basis for your authority – for example, a court order has granted you the power to access this information. Any legal basis will need to be outlined and evidenced clearly.
 - any information that will distinguish the person from others with the same name, such as their NHS number or National insurance number.
- 3. Keep a copy of your request** and any proof of postage/delivery.



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The organisation must respond to you within one month. However, in certain circumstances they can have an extra two months – such as when the request is complex, or if more than one request has been submitted. The organisation should provide the data free of charge, but they may charge for additional copies. They can also charge a fee if the request is ‘manifestly unfounded or excessive’ (it is clear that it is not a reasonable request). However, any fee should be fair for the costs of providing the requested information.

The organisation will usually respond in one of two ways:

- They will agree to share the information with you and outline how this will be arranged.
- 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 25.**



Information you might need to access

On the next few pages there are some examples of information you might need to access when you're supporting someone with dementia, along with advice on how you can do this.

1

Medical records

There are times when you may need to access the medical records of someone with dementia. This could be for different reasons, such as:

- to help them manage medications
- to help with making decisions about their care and treatment
- for a legal reason – for example, making a complaint, or applying for funding such as NHS continuing healthcare funding.

To access the person's medical records you need to make a subject access request to the relevant organisation (see '[Requesting information: Subject access requests](#)' on page 12). For example, you might send a subject access request to the person's GP surgery or hospital where they are receiving treatment. If you have a relevant legal power or the person's consent you should be given access. If you don't have this, you will need to explain clearly why you need access to the information and why this is in the person's best interests.



Care assessments

1

To access care and support, many people with dementia will have a care needs assessment from social services. People close to them often want to see the results of this assessment. It can also be helpful to know what care needs have been identified 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 grant people access.

- In England the local authority has a duty to provide the person and their carer with a copy of their assessment, as well as anyone else a person with dementia asks them to give a copy to.
- In Wales local authorities must offer to give a person with dementia, or anyone with authority to act on their behalf, a copy of the assessment. If there is no one with legal power to act on the person's behalf then anyone the local authority believes to be acting in the person's best interests (such as a carer or family member) should be offered a copy.
- In Northern Ireland there is a requirement that an assessment should be shared with a person with dementia and carers as soon as possible.

If these obligations are not met, you have a right to complain to the local authority or local health and social care trust and ask for access. Alternatively you can still make a subject access request. Someone who may not automatically be entitled to this information (such as a family member who is not a carer) may also make a subject access request, and also has the right to complain if they feel this has not been handled correctly.



Care home records

When a person with dementia is living in a care home, their family members and close friends often want to see their care home records. If the person is able to make this decision themselves, they can consent to someone else viewing the records. If they cannot consent, then those with an appropriate legal power should be allowed access if it is needed to carry out their role. For example:

- An attorney or deputy under an LPA or EPA for health and welfare may need to keep up to date with the person's care so that they are able to make any decisions relating to their care and treatment if needed.
- An attorney, deputy or controller with power over a person's finances may need this information to assist in their role, to ensure that they are spending the person's money wisely or to support a financial assessment.

Often care homes will share this information without needing a formal subject access request. However, if a conversation with the care home does not lead to access in these cases, you can make a formal request (see **'Requesting information: Subject access requests' on page 12**).

If someone doesn't have a legal power or consent from the person it can be more difficult to access these records. However, they can still ask, and put in a subject access request if this is needed. If they do, it's important to give a clear explanation of why they need this information and why it is in the person's best interests to share this.







2

Sharing information

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 or social care professional, for example.

Information you may need to share

In many cases, even if you can't access information on a person's behalf, you can still share information. On the following pages you can read examples of situations where you may need to share information on behalf of someone with dementia, and the type of information you can share.

2

Sharing concerns with someone's doctor

There may be times when you wish to speak to another person's doctor (such as their GP or neurologist) but the person is unable to consent and you don't have a legal authority. You might want to do this because you are concerned about their memory or health and they won't go and see the doctor themselves, for example.

Other people, including healthcare professionals, may tell you that you cannot speak to another person's doctor due to issues of confidentiality. However, this is not true. You cannot access the person's information, but you can still share information with them and they should still listen to your concerns. However, it's important to know that the doctor can tell the person that you have contacted them and what was discussed.

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

A person with dementia may want or need support to fix a problem with their utilities or services (such as their phone line, internet, gas or electricity). If you have a legal power or the person's consent you can easily contact the utility or service company on the person's behalf and report the fault.

If you don't have a legal power to act on the person's behalf and they are unable to give their consent, it is still possible to report the fault. Sometimes companies refuse to speak to



other people (third parties) in these cases due to confidentiality. However, although they cannot disclose information to you, you have a right to share information with them and they should listen to your concerns.

If you have problems sharing this information with companies, you can make a complaint – see **‘Making a complaint’ on page 25**.

Cancelling utilities when someone moves into a care home

When someone moves into a care home, as well as dealing with the range of emotions you may feel, there are practical things to consider. Knowing what to do can help at this difficult time.

For instance, if the person leaves their home empty when they move into the care home, it may be necessary to inform the providers of their utilities, such as their phone line, electricity, gas and insurance. The person themselves may not be able to do this or may need support.

If you have an appropriate legal power, or the person’s consent, you can contact the organisation and inform them of the person’s change in circumstances. The company should listen to you and act accordingly, though they may ask for evidence of the person’s consent or legal power. If you have already been in contact with a company before and have 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 with dementia because the organisation does not need to disclose any information to you. You’re simply sharing information with the company.

The organisation may require some form of proof that the person has moved, such as a letter from the care home, or a copy of the care home contract.





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.

If you have legal power you may have the power 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 made in their best interests. By law, the decision maker – for example, the doctor or social worker – must consult those closest to the person. This includes carers, family members and friends. You therefore have a right to be involved in decisions made on behalf of a person with dementia.

To be consulted, you should be able to share your thoughts and feelings. Importantly, because you know the person, you should be able to share what you think they would want and what you think is best for them. This means you have a right to share information, although it doesn't include a right to access information, or make the decision.





3

Making a complaint

There may be times when you contact an organisation on behalf of a person with dementia and you are not able to access or share information in a way that you wish. If you feel that the organisation has acted wrongly, you can complain.

The following process shows how you can complain if you were wrongly denied access to, or the ability to share, a person's information.

You might do this, for example, if you have a legal power or permission and have shown this to the organisation, but they did not allow you to access or share information.

3





3



A decorative background featuring a close-up of red flowers with yellow centers in the upper right, and a person's arm in a grey sweater in the lower left. A large white rectangular area contains the main text.

4

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

4

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–4pm 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.

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

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 (9.30am–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)
www.ombudsman.org.uk

4

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.

Solicitors for the Elderly (SFE)

0844 567 6173
admin@sfe.legal
www.sfe.legal

Solicitors for the Elderly 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: Office of the Public Guardian and Irene Chenery, Consultant, Harrison Drury Solicitors, member of Solicitors for the Elderly

It has also been reviewed by people affected by dementia.

To give feedback on this booklet, or for a list of sources, email [**publications@alzheimers.org.uk**](mailto:publications@alzheimers.org.uk)

This booklet can be downloaded from our website at [**alzheimers.org.uk/publications**](https://alzheimers.org.uk/publications)

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We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit alzheimers.org.uk or call our **Dementia Connect support line** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on **0330 333 0804** or go to alzheimers.org.uk/donate



Office of the
Public Guardian



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alzheimers.org.uk

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