

Accessing and sharing information

Acting on behalf of a person with dementia





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Introduction

Everyone shares their personal information with organisations. For example, with gas and electricity suppliers, sorting out a query with the bank, claiming a benefit or arranging a repeat prescription, personal information is provided. There is an expectation that these organisations keep this information safe.

When someone has dementia, they may be able to keep managing their own affairs in the early stages of the condition. But, as their dementia progresses, there will probably come a time when the person is no longer able to do so. They are said to lack the ‘mental capacity’ to decide for themselves (see ‘Legal powers’ on page 4).

Dealing with this situation can seem difficult. This booklet aims to provide advice to help you when a person with dementia needs help with their affairs. It gives practical advice on handling someone’s personal information to help them manage their affairs, or when managing their affairs for them. ‘Personal information’ or ‘personal data’ here refers to things like medical records, bank or credit card details, and utility bills. (This list is not exhaustive.) The information is relevant to people living in England, Wales and Northern Ireland.



Everyone expects organisations to look after their personal data securely and to be very careful about who they share it with – they have a duty to do this. This duty is set out in law under the Data Protection Act 1998. Someone with dementia may be more vulnerable and susceptible to financial abuse, so this duty of confidentiality becomes particularly important. This is why, when someone has lost the capacity to manage their own affairs, there are tighter restrictions on who can access their data. In some circumstances you may feel that you have the right to know something, but the law may not support this.

This booklet should help you understand what you can and cannot do when managing someone else's affairs. It explains your rights and provides practical information. It may help explain why an organisation is not sharing someone's data, and what you can do about this. Your rights and what you have the power to do will depend on what legal powers you have. These are described on page 4.



Legal powers

Your legal right to access and share someone else's personal information on their behalf depends on the circumstances, in particular whether the person has mental capacity. Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to 'lack capacity', and this may be the case for a person with dementia. The person may have capacity but still want you to speak to someone else for them. Or they may lack capacity and you will need to make a decision on their behalf, perhaps because they have appointed you as an attorney. In all cases you must do what the person wants or what is in their best interests. For more information about this see factsheet 460, Mental Capacity Act 2005.

This booklet refers to three of the most common scenarios:

1 When you have a legal power

This section outlines the various types of legal power that someone can have to manage the affairs of a person with dementia, and how this can be used to access the person's information. For example, someone with a power of attorney may need to access a person's bank account or care records.



2 When you have permission to manage someone else's information but no legal power

There may be times when a person with dementia asks you to help them manage their affairs and gives you informal permission to speak to an organisation on their behalf to access their information. For example, someone may let you speak to a utility company on their behalf to discuss a bill.

3 When you can't get permission and have no legal power

There may be a time when someone lacks mental capacity so can't give you permission, and you don't have legal power either. You should still be able to act and help the person, though in a much more limited way.

In the following sections you will find case studies showing how each possibility works in practice. In Section 4 on page 26, there is information about what to do if things go wrong and you wish to make a complaint.





The Alzheimer's Society Dementia Friendly Communities programme aims to improve inclusion and quality of life for people with dementia.

A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. This includes people having the confidence to do everyday things such as banking and shopping. It is also a community in which people who wish to support a person with dementia are empowered to do so. As part of this programme Alzheimer's Society is working with representatives across a number of sectors that want to become dementia friendly.

This booklet has been developed to enable those supporting people with dementia to understand their rights in the community when dealing with organisations. Alzheimer's Society has worked with a number of different organisations, from government departments to banks, utility providers as well as lawyers and other charities to produce this guidance. For more details see 'Acknowledgements' on page 31.





1

When you have legal power

There are many different types of legal power that a person can get that will allow them to manage affairs, access information and make decisions for a person with dementia. These are outlined in Tables 1 and 2. These legal powers are all different, and won't all be relevant to every situation.

Step 1 Check whether you have legal power to act

If you already have a legal power, it's important to check whether it is relevant to your situation, in terms of the organisation you are dealing with and the information or data in question. Table 1 lists the types of legal power available in England and Wales. Table 2 lists types of legal power in Northern Ireland.



Table 1: Legal powers in England and Wales

Name	Used for	Details	Information
Lasting Power of Attorney (property and affairs)	Making decisions about finances, including managing a bank account or selling a property; accessing the person's relevant information.	Needs to be registered with Office of the Public Guardian before use. Can be used while the person is still able to make decisions for themselves.	Contact Office of the Public Guardian (see 'Other useful organisations' on page 27). See factsheet 472, Lasting Power of Attorney.
Lasting Power of Attorney (health and welfare)	Making decisions about where to live, or day-to-day care and treatment; accessing the person's relevant information.	Needs to be registered with Office of Public Guardian before use. Can only be used if the person you are helping can no longer make decisions for themselves.	Contact Office of the Public Guardian (see 'Other useful organisations' on page 27). See factsheet 472, Lasting Power of Attorney.



Name	Used for	Details	Information
Enduring Power of Attorney	Making decisions about property and affairs, including financial affairs and accessing the person's information.	Can no longer be created but will still be accepted if created before 1 October 2007.	Contact Office of the Public Guardian (see 'Other useful organisations' on page 27).
Ordinary / General Power of Attorney	Only covers decisions about property and finance.	Limited power and can only be used while the person is still able to make decisions for themselves.	Contact your local Citizens Advice Bureau (see 'Other useful organisations' on page 27) or a solicitor.



Name	Used for	Details	Information
Deputyship	Court order appointing a deputy to deal with financial affairs or a welfare decision. Someone can only apply to become a deputy if the person has lost mental capacity and they had not previously made either type of power of attorney.	Can only be used to make decisions as specified in the Court order.	Contact Court of Protection (see 'Other useful organisations' on page 27). See factsheet 530, Becoming a deputy for a person with dementia.



Table 2: Legal powers in Northern Ireland

Name	Used for	Details	Information
Enduring Power of Attorney	Making decisions about property and affairs, including financial affairs and accessing relevant information.	Needs to be registered with the Office of Care and Protection (Patients Section) before use.	Northern Ireland procedures differ from other UK jurisdictions. More information can be found at www.courtsni.gov.uk/en-gb/services/ocp See factsheet NI472, Enduring Power of Attorney and Controllership.
Controllership	A controller can be appointed to manage someone's financial affairs when there is no Enduring Power of Attorney and the person can no longer manage their affairs.	A controller must follow guidance as issued by the Office of Care and Protection.	Northern Ireland procedures differ from other UK jurisdictions. More information can be found at www.courtsni.gov.uk/en-gb/services/ocp See factsheet NI472, Enduring Power of Attorney and Controllership.



Step 2 If you are acting for someone else under one of these legal powers you will need to:

- provide the original or a certified copy of the legal document
- provide identification; the organisation will tell you what they require
- tell the organisation what personal information or data about the person you need and why.

When using a legal document you can expect:

- to be treated as though you are the person you are representing
- that the organisation will have a clear policy for accepting legal documents
- to be spoken to with respect
- to be referred to the most appropriate member of staff to deal with your query
- to be given clear advice about how to give or receive information.



Case study

Lynda has a property and affairs Lasting Power of Attorney (LPA) for her husband Mike, who has advanced Alzheimer's disease and can no longer manage his financial affairs.

Once the LPA was registered with the Office of the Public Guardian, Lynda took it to the local branch of Mike's bank so that she could access his bank accounts and information about his finances.

At the bank Lynda was asked to show them the original LPA document and her own identification. Once this was done, the bank discussed her husband's finances with her and the various banking options that were now available to them. From then on Lynda was able to manage and deal with her husband's finances at the bank.



Accessing the person's information

As an attorney, deputy or controller you have the right to access information that is held about the person you represent, to help you carry out your role. If you request this information from an organisation, this is often referred to as making a 'subject access request' on behalf of someone else.

For example, if you have a property and affairs Lasting Power of Attorney, you may need to access information about the person's property, finance or healthcare arrangements to help you make legal or financial decisions on their behalf. If you have a health and welfare Lasting Power of Attorney, you should have the right to access relevant medical information of the person you represent in order to help you make an informed decision about their care and treatment.

To make a subject access request on behalf of the person you represent, you should write to the organisation directly. You can ask for all of, or only a particular type of, the information they hold about that person. You may need to show them the LPA or other document you hold or a certified copy to prove that you are acting as an attorney.

There is more information about how to make a subject access request on the website of the Information Commissioner's Office (see 'Other useful organisations' on page 27).



Case study

Tony is an attorney for his mother, Jenny, who has dementia. He has a property and affairs Lasting Power of Attorney. Recently Jenny moved into a care home following a stay in hospital. She was turned down for the NHS continuing healthcare funding and Tony wishes to appeal this decision.

In making his appeal Tony felt that it would help if he could have a copy of his mother's medical records, as well as copies of the assessments that have been carried out. He made a subject access request by writing to his mother's clinical commissioning group outlining the records that he wanted. He also provided his mother's details (name, address and NHS number) as well as his own details.

After a few weeks Tony received the records that he requested and these helped him with the appeal.



2

When you have permission to manage someone else's information but no legal power

If you are acting for someone else but you don't have one of the legal powers outlined in Section 1, the Data Protection Act will not prevent you from accessing and updating information about another person, as long as you have their permission.

Permission could be given verbally. For example, the person can confirm to the organisation verbally that they give permission for you to act on their behalf and receive information. Alternatively, someone could put this in writing to be shown or posted to the organisation.



The Information Commissioner's Office (ICO) has information about how to make a request for someone's personal information. This can be found on their website or via their helpline (see 'Other useful organisations' on page 27). The ICO expects organisations to act reasonably and sensibly in response to requests for information, and to consider each request on its particular circumstances.

You should:

- get the person's consent, either verbally or in writing
- provide the organisation with proof of the permission that you have been given, for example a letter or verbal confirmation from the person over the phone
- explain to the organisation what you need to do and why
- ask them how they can support you
- expect to be asked to produce proof of your identification.



Case study

Sunita's close friend Judy has dementia. The two of them regularly go shopping together and Sunita often pops round for a cup of tea and a catch-up.

One day Sunita tried to ring Judy but couldn't get through. After a few more tries she was concerned and went round to check on her. When she got there she noticed there was a problem with the phone line.

Sunita asked Judy about it, and Judy explained that she had tried to contact the phone company but she couldn't do this on the phone as it didn't work so wasn't sure what to do. She asked Sunita to help her. Sunita used her mobile to contact the phone company, with Judy's permission.

The phone provider confirmed with Judy that she was happy for Sunita to help sort out the problem. This meant Sunita was able to arrange for someone to check the problem with the phone line.





3

When you can't get permission and have no legal power

When you can't get permission to act for an individual (perhaps because they no longer have capacity to give permission), organisations will understandably be cautious about releasing that person's personal information to you. This will be for many reasons, including confidentiality and the Data Protection Act.

Generally an organisation won't be able to disclose any information to you in these situations. However, there are some circumstances where, even though you do not have permission to act, organisations should be able to help you. This doesn't mean that they can disclose the person's information to you, but they should be able to listen to you and allow you to share information with them. An example of this is an emergency situation where staff are being asked to receive information, rather than disclose information, for example when a problem is being reported.



Case study

Peter's neighbour Chris has Alzheimer's. Chris's condition is very advanced and as a result he can no longer manage finances or his everyday living arrangements and care. He is receiving a lot of care and support in his own home.

One day Peter got home from work and noticed that Chris's guttering had come away in a storm and had caused damage to his house. Knowing that Chris is vulnerable, Peter went round to see what he can do to help.

Chris wasn't able to give permission to Peter to act, but as there was water damage and a number of other issues Peter felt that he must do something.

On his neighbour's behalf Peter contacted the insurance company. Although he did not have a legal power to act and could not get permission from Chris, the insurance company were able to listen to him and take note. Peter was also able to contact the local authority, who are in charge of Chris's care, so that they were aware of the situation and could help further.

3 When you can't get permission and have no legal power



Case study

When Priya's father Kumar moved into a care home, it happened so quickly that the Lasting Power of Attorney that Kumar made, appointing her as his attorney, had not yet been registered.

Kumar's home was then empty, so Priya wanted to cancel her father's utilities and phone and TV contracts. As the LPA was not yet registered Priya was concerned that she wouldn't be able to do this and her father would have to continue to pay for services that he was no longer receiving.

Priya contacted the various organisations and explained to them that she needed to inform them that her dad had moved and the home was empty so that utilities could be stopped. She also sent confirmation that Kumar had moved and that the home would no longer be occupied.

The companies did not need to share any information with Priya, but they were able to listen to her and accept the evidence that showed Kumar had moved, so they were able to act accordingly.

If the decision is about the person's health and welfare, for example treatment or care, the professional involved should consult with you and others close to the person. This does not give you the right to view the medical or care records of the person with dementia without a legal power or the person's consent. However, it does mean you should be asked for your views on the decision being made, and be given the chance to share what you feel is best for the person with dementia.



Other carers, relatives and close friends should be included as appropriate. This should give you the opportunity to share your views about what the person would want, and discuss what you feel would be in their best interests.

Case study

Trevor's dad Mark has had dementia for several years. Mark was receiving care and support at home, but following a fall he was in hospital for a number of weeks.

As part of the discharge process, the hospital had to consider the level of care that Mark would then need, and where he should live to receive this care. Because of the progression of his dementia Mark was not able to make this decision, and Trevor had no legal power.

The hospital felt that Mark needed more care and supervision and that he would be best to move into a care home. Although Trevor had no legal power, he was able to liaise and speak to the hospital social worker about the discharge and where his dad should move.

The social worker discussed Mark's care needs and level of care with him and Trevor, and Trevor agreed that the decision was for the best. Trevor was then able to work with social services to identify a care home that was suitable and near to him.

3 When you can't get permission and have no legal power



In the longer term:

- If possible, speak to the person about them creating a Lasting Power of Attorney (England and Wales) or an Enduring Power of Attorney (Northern Ireland).
- If this is not possible as they are not able to make this decision then you may wish to consider applying to get a court order and become the person's deputy (in England and Wales) or to become the person's controller (in Northern Ireland).

Information about these options is available from the Office of the Public Guardian (England and Wales), the Office of Care and Protection (Northern Ireland) and Alzheimer's Society. See 'Other useful organisations' on page 27.



4

4

If things go wrong

If things go wrong

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 then you can complain. For example, you may have shown them your legal power, or the permission you had, and they still wouldn't speak to you.

It is always best in the first instance to complain to the organisation directly. Information about how to do this will be in the company's complaints procedure, which you can usually get from their website or by calling them. If you are not satisfied with their response, you should report your concern to the Information Commissioner's Office (see 'Other useful organisations' on page 27).



5

Other useful organisations

Citizens Advice Bureau (CAB)

Various locations

W www.citizensadvice.org.uk
www.adviceguide.org.uk (online information resource)

Your local CAB can provide information and advice in confidence or point you to further sources of support. Trained CAB advisers can offer information on benefits in a way that is easy to understand. To find your nearest CAB, look in the phone book, ask at your local library or look on the website (above). Opening times vary.



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E casework@ico.org.uk

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2nd floor

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T 029 2067 8400

E wales@ico.org.uk

W www.ico.org.uk/about_us/our_organisation/wales

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3rd Floor

14 Cromac Place

Belfast BT7 2JB

T 028 9027 8757

E ni@ico.org.uk

W www.ico.org.uk/about_us/our_organisation/northern_ireland

The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.



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Room 2.2A, Second Floor
Royal Courts of Justice
Chichester Street
Belfast BT1 3JF
T 028 9072 4733

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

PO Box 16185
Birmingham B2 2WH
T 0300 456 0300 (9am–5pm weekdays)
E customerservices@publicguardian.gsi.gov.uk
W www.gov.uk/office-of-public-guardian

The OPG supports and promotes decision-making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005. It provides free booklets on Enduring Powers of Attorney, Lasting Powers of Attorney and Deputyship.



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Solicitors for the Elderly is an independent, national organisation of lawyers, such as solicitors, barristers, and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers.



Acknowledgements

Alzheimer's Society would like to thank the organisations below for their endorsement of the document, and their invaluable assistance in developing the content:

The Office of the Public Guardian (OPG) supports and promotes decision-making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005. The OPG chaired and hosted stakeholder group meetings. They were instrumental in producing the first drafts of the booklet and ensuring that the stakeholder group stayed on target.

The Information Commissioner's Office (ICO) is the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. The ICO offered valuable input in ensuring that the law and people's rights are accurately represented in the booklet, specifically in relation to the Data Protection Act 1998.



A number of other organisations also contributed to the development of this document, by offering their expertise and knowledge at the draft stages, as well as reviewing the final document:

- Barclays
- British Bankers' Association
- BT
- Building Societies Association
- Information Commissioner's Office
- International Longevity Centre – UK
- The Law Society
- Lloyds Banking Group
- Mental Health Foundation
- NHS England
- Office of the Public Guardian
- Solicitors for the Elderly



This booklet has been reviewed by health and social care professionals, as outlined in the Acknowledgements section. It has also been reviewed by people affected by dementia. We would like to thank them for their generous and valued contributions.

It can be downloaded from our website at **alzheimers.org.uk/sharinginformation**

Sources are available on request.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions

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First published: November 2014
Next review due: November 2017

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.

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit alzheimers.org.uk or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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