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# FAQ: Dementia and Carers

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# Healthcare and Social Care Funding

**What help and support are available if someone from your family has dementia?**

There are care and support available from the NHS (for example, support from the Older People's Mental Health Team) and the adult social services of your local council (such as help with washing and dressing).

In addition, both the NHS and your local council may offer funding for the services that your family member receives.

# What is the difference between NHS and local council funding?

Funding from your local council is means-tested and therefore depends on the financial situation of the person you are caring for.

By contrast, NHS funding is purely needs-based, which means that you may apply for the funding if the person you are caring for has ongoing and complex health needs.



# What is the NHS Continuing Healthcare (CHC)?

CHC is a package of care that is arranged and funded solely by the NHS. Such care is provided to an individual aged 18 or over, to meet health and associated social care needs that have arisen as a result of disability, accident or illness (including dementia).

Importantly, CHC is free, unlike support provided by local authorities for which a financial charge may be made depending on your income and savings.

## What costs are covered by CHC?

CHC covers the costs of healthcare and other personal care, such as the expense of specialist therapy and helps with washing and dressing.

CHC may also include accommodation (if the member of your family lives in a nursing home or care home) and support for you as a carer (if you are looking after your family member at home).



## When should a person be considered for CHC?

When a member of your family is diagnosed with dementia, you can speak to your GP to find out more about CHC.

Your local council may also refer you to your local Clinical Commissioning Group (CCG) after they have reviewed the health or social care needs of your family member as part of a community care assessment.

## What is the eligibility for CHC?

To qualify for CHC, the person you are caring for must be assessed and found to have a primary health need by your local CCG.

## What is a primary health need?

Having a primary health need is not about a specific condition or diagnosis, nor about who provides the care or where the care is provided. Instead, it is concerned with the level and type of an individual's day-to-day care needs taken in their totality.

Therefore, a person diagnosed with dementia will not automatically qualify for CHC. Indeed, the Department of Health and Social Care cautions that CHC is only available in a relatively small number of cases with high levels of health needs.

However, you should bear in mind that dementia is, alas, a progressive condition and so the health needs of the person with dementia are likely to increase over time.



# What is the assessment process for CHC funding decisions?

There is a two-stage assessment process:

- initial screening (using the checklist tool)
- full assessment by a multidisciplinary team (MDT) (using the decision support tool)

In exceptional cases (where the person's condition is rapidly deteriorating), a fast-track pathway tool will be used instead of the two-stage process.

## How long does the decision-making process generally take?

The CCG will normally respond to MDT recommendations within 48 hours and the overall assessment and eligibility decision-making process would not exceed a maximum of 28 calendar days from the date the CCG receives the checklist concerning eligibility.

Should the process take longer, the extension would normally be communicated to you.

## How will a person's eligibility be communicated?

You will generally be informed in writing as soon as possible as to whether or not a person is eligible for the CHC, the reasons for the decision, the details of who to contact should you seek further clarification, and how to request a review of the eligibility decision.



## Are there alternative sources of funding if CHC is not available?

If the person you are caring for does not qualify for CHC but is assessed as having some health needs, there is an alternative funding option, namely NHS-funded nursing care (FNC).

FNC is a standard rate contribution towards the cost of providing registered nursing care in a nursing home, with the rest of the expense covered by yourself or your local council.

Additionally, your local council may be able to provide funding, depending on the financial situation of the person being cared for.

# Carers and Care Assessment

Nearly 900,000 people live with dementia in the United Kingdom. Most of the support and care given to these people is provided by their family members and loved ones, who can be considered 'carers'.



## What is a 'carer'?

A carer is defined by the Care Act 2014 as an unpaid “adult who provides or intends to provide care for another adult” who needs care.

## What constitutes 'an adult needing care'?

According to the Statutory Guidelines, the definition of 'an adult needing care' arises from 'physical, mental, sensory, learning or cognitive disabilities or illness, substance misuse or brain injury' (6.104)

## What will be considered 'care'?

The care does not have to be substantial or regular. Additionally, it is not limited to physical care, it can also be emotional.

## Why does it matter that I am considered a 'carer'?

As a carer, your wellbeing will be considered alongside the wellbeing of the person who you care for. You may receive support to meet your needs, if there are eligible needs.

In order to qualify for this support, you will need to undertake a free care assessment.

# What is a Care Assessment?

A Care Assessment is free and optional.

Your local authority can offer you one, if it appears to them that you need one. But you can choose to accept or reject it. In case they do not offer you a care assessment, you can request it.

The assessment consists of a conversation between you and someone from your local authority, so they can assess your eligible needs.



# What are the benefits of a Care Assessment?

- It might help you identify what your needs are
- It can provide access to information as to what services are available to help you
- Depending on the type of help or support, the outcome of the assessment may help with your relationships, employment and recreational activities
- It may entitle you to funded support



## What help is available to me as a 'carer'? (Part 1)

Through the care assessment, carers are entitled to the creation of a support plan. A support plan will assist in the management of your mental, physical and emotional wellbeing while you care for another person.

The support plan will offer information on various topics, including:

- Getting someone to take over caring so you can take a break, otherwise known as respite
- Access to programs which help you relax, such as a gym membership or exercise classes
- Covering taxi fares if you do not drive
- Training on how to provide physical care, such as safe lifting and personal care
- Advice about benefits for carers

# What help is available to me as a 'carer'? (Part 2)

Support plans can result in three forms of monetary support.

They are:

- a Personal Budget
- the Carer's Allowance
- the Carer's Credit



## What is a Personal Budget?

The personal budget is a monetary sum from your local authority which can be spent on wellbeing items for yourself. These include gym memberships, or hobby items such as a shed for gardening while you are caring.

The Care Act 2014 requires local authorities to be aware of your needs as a Carer and requires that it provides you with support to enable effective care of the person you support.

→ Eligibility criteria can be found in the Guide

## What is a Carer's Allowance?

The Carer's Allowance is a benefit provided by the government directly to Carers.

It is a monetary sum of £67.60 per week, provided if you support someone for at least 35 hours per week.



## What is the Carer's Credit?

The Carer's Credit is a National Insurance credit which helps with gaps in your National Insurance record.

This will help with your state pension in the future, as it explains why your earnings may be less when you are caring for another person.

Your income, savings, or investments do not affect eligibility for Carer's Credit.

→ Eligibility criteria can be found in the Guide



# Planning Ahead

When a loved one has dementia, it can be useful for them to create a lasting power of attorney (LPA).

Under an LPA, your loved one can give you legal permission to make decisions on their behalf.



# What is an LPA?

There are two types of LPA:

- financial LPAs
- health and care LPAs.

Creating a financial LPA will allow you to make financial decisions on behalf of your loved one.

There are also health and care LPAs which would allow you to make decisions about their health and welfare when they become unable to make those decisions for themselves.

→ How to create an LPA can be found in the Guide



# How do I create an LPA? (I)

You can create an LPA through a solicitor, who will ensure that it is validly created and registered. Alternatively, you can create an LPA yourself.

You can do this by going onto the government website and filling out the LPA forms, available at: <https://www.gov.uk/power-of-attorney/make-lasting-power>

You can choose to create the LPA online or to print out the forms and fill them in on paper. In order to be valid, the LPA must also be registered with the Office of the Public Guardian.

## How do I create an LPA? (II)

If you create your LPA online, in order to register it you will need to print out your LPA forms, ensure that they have been signed by all relevant parties (the person creating the LPA, the appointed attorneys, the witness and the certificate provider) and send the forms to the following address:

Office of the Public Guardian,  
PO Box 16185,  
Birmingham,  
B2 2WH

On the other hand, if you fill the LPA forms on paper, in order to register them you must ensure that they have been signed by all relevant parties and send the forms to the address noted at the end of the LPA form.

## When can an LPA be created?

An LPA can be created by your loved one at any time, so long as they have the capacity to do so. This means that an LPA can be created before or after they have been officially diagnosed with dementia.

Your loved one will have legal capacity to create an LPA when they are able to make decisions for themselves. In other words, when they can remember and weigh up all of the relevant information about the LPA in order to decide whether to go ahead with it.

If they are unable to do so, they cannot create a valid LPA. If this is the case, please see the information below on Deputyship.

## How much will it cost to create an LPA?

There is a fee of £82 to register an LPA. This means that if you want to create both a financial LPA and a health and care LPA it will cost £164.

Nevertheless, you may be able to get a discount if you earn less than £12,000 and you may not have to pay at all if you receive certain benefits such as Income Support.

If you choose to use a solicitor to create an LPA, it is likely to be more expensive as the lawyer will also charge for their time.

# Advance Decisions

An advance decision allows a person to refuse a specific type of medical treatment in the future in particular circumstances.



## Can a person with dementia make an advanced decision before they get a diagnosis?

Yes, a person with dementia can make an advance decision before they receive a diagnosis of dementia.

However, an advance decision is a refusal of specific, named treatments, so it may be more helpful to have a diagnosis before making their advance decision as it would allow them to be certain of which treatments they would like to refuse.

Ultimately, a diagnosis is not required as long as the person with dementia is aware of what specific types of treatment they wish to refuse.

## What if the doctors disagree with an advanced decision and believe that it isn't in the patient's best interests?

A doctor disagreeing with an advance decision will not have any effect on the advance decision, if it is a clear and valid advance decision which has been made in accordance with the Mental Capacity Act.

It will be valid if it has been created following the procedures in the Act, which will also make it legally binding. Therefore, a healthcare professional must follow the advance decision and they could be taken to court if they fail to comply with it.

However, if you are receiving treatment and your advance decision is not clear as to whether it covers a particular type of treatment, then treatment will be provided to you.

## Can an advance decision override a lasting power of attorney?

If the lasting power of attorney is made first, a valid and applicable advance decision will override your lasting power of attorney as it is a more recent reflection of the person with dementia's wishes.

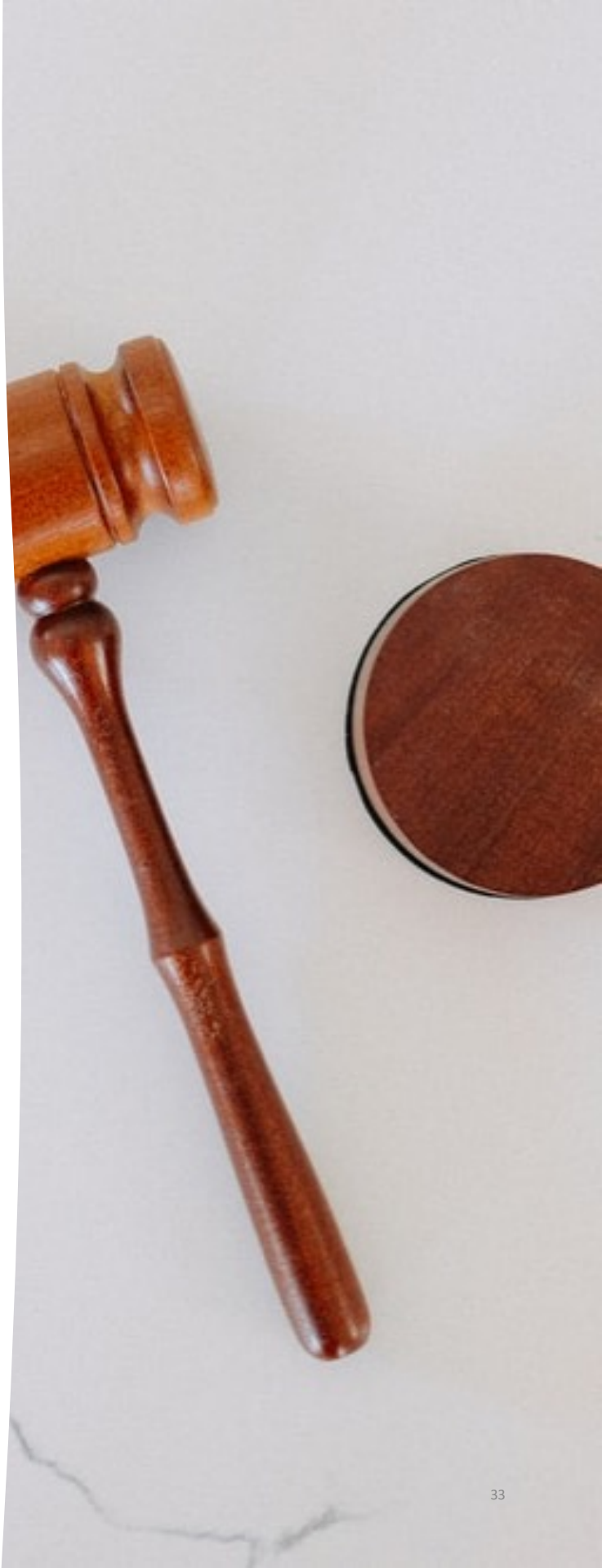
Similarly, if the advance decision is made first, the lasting power of attorney can override the advance decision.



# Deputyship

## What is the Court of Protection?

It is a specialist court which looks after individuals which lack capacity to make decisions for themselves. The court gives powers to a certain individual to make certain decisions on behalf of someone else. If you are acting on behalf of somebody else, you are called a deputy.



## When would the court need to appoint a deputy?

If you have not made an LPA and you lose capacity, you will need to apply to the protection so they can appoint a deputy. They help make decisions with the person.

## What does losing capacity mean?

Losing capacity occurs when a person struggles to decide for themselves. They have a mental issue that affects their everyday decisions. They may have Alzheimer's, Dementia or a brain injury.

The Court works with doctors to decide whether a person lacks capacity. The level of capacity are determined by specific capacity tests.

## Who can be appointed as a deputy?

Anyone over the age of 18 can be appointed as a deputy. This could be your solicitor, family member or close friend.

The court will look for someone who will carry out the role effectively.

Property and affairs deputies need to have the skills to make financial decisions for someone else.

## Can you have more than one deputy?

It is possible to have more than one deputy. They can work together and must all agree on the decisions. Although you can have deputies that make the decisions on their own without conferring with the other deputies.

## When should a property and affairs deputy be appointed?

If a person lacks mental capacity to make decisions about their property and financial affairs, and they do not have an LPA, they will need to apply to appoint a deputy.

This will allow them to:

- Deal with any income
- Pay any bills and debts
- Deal with any cash assets (e.g. bank and building society accounts)
- Manage or sell property
- Deal with any capital assets and make any investment decisions

## When should a personal welfare deputy be appointed?

The court makes deputyship orders when:

- a) important and necessary decisions cannot be carried out without the courts' authority, or
- b) there is no other way of dealing with the matter in the best interests of the person concerned to make welfare decisions

## When should a personal welfare deputy be appointed?

A series of forms will need to be completed and sent off to the Court of Protection, which must be supported with a doctor's mental capacity assessment.

## What costs are involved with a deputyship?

- The mental capacity test can cost between £50 - £300.
- The Court of Protection charges an application fee of £365 for each type of application.
- If you need a hearing for a case the Court asks you to pay £485.
- If you have been appointed as a deputy you need to pay an annual supervision fee. This is £320 for general supervision or £35 for minimal supervision. Minimum supervision only applies to people who have less than £21,000.
- New deputies must pay a £100 assessment fee.

# What duties can a deputy have?

Deputies must act in the best interest of the person they are representing.

They must make sure that they:

- Make decisions which are in the person's best interests
- Consider what the person has done in the past when they had capacity
- Apply a high standard of care which might mean including other people, such as getting advice from relatives or doctors
- Do everything they can to help the person understand the decision
- Record major decisions in the annual report
- Make sure that their own property and money is separate from the person's
- Keep records of the finances they manage on behalf of the person.

# What can a deputy not do?

These are some examples of what a deputy cannot do:

- Restraining the person, unless it is to stop them from harm
- Stopping life-sustaining medical treatment
- Taking advantage of the person's situation by, for example, profiting from a decision the deputy made on behalf of the person
- Making a will for the person, or changing their existing will
- Making gifts (if don't fall within limited exceptions), unless the court order says you can
- Holding any money or property that belongs to the other person in their own name



# Signposting

Name of service:	Type of service:	Contact details
Age UK	Providing companionship, advice & support for older people	<p>Tel: 0800 678 1602 (advice line open 8am–7pm every day)</p> <p>Email: <a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a></p> <p>Website: <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a></p>
Alzheimer's Society	Help with care	<p>Support Line Tel: 0333 150 3456 Tel: 1800 1 0300 222 1122 (for those with speech or hearing difficulties and have a textphone or an adapted computer and use Text Relay)</p> <p>Lines open: Monday – Wednesday 9am – 8pm Thursday &amp; Friday 9am – 5pm Saturday and Sunday 10am – 4pm</p> <p>General Enquiries Tel: 0330 333 0804 8am – 10pm lines open every day (except Christmas day) Online: <a href="https://www.alzheimers.org.uk/form/contact-us-general-enquiries">https://www.alzheimers.org.uk/form/contact-us-general-enquiries</a></p> <p>Online support messaging: <a href="https://dementiaconnect.alzheimers.org.uk/?_ga=2.128451214.388044294.1607611655-1960316724.1584975499">https://dementiaconnect.alzheimers.org.uk/?_ga=2.128451214.388044294.1607611655-1960316724.1584975499</a></p> <p>Website: <a href="https://www.alzheimers.org.uk/get-support/help-dementia-care/looking-after-yourself#content-start">https://www.alzheimers.org.uk/get-support/help-dementia-care/looking-after-yourself#content-start</a></p>
Alzheimer's Society (cont'd)		<p>Financial care and support website: <a href="https://www.alzheimers.org.uk/get-support/legal-financial/who-pays-care">https://www.alzheimers.org.uk/get-support/legal-financial/who-pays-care</a></p> <p>Replacement (respite) care website: <a href="https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-more-resources#content-start">https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-more-resources#content-start</a></p> <p>Practical guide for caring for a person with dementia: <a href="https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide">https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide</a></p>
Carers Trust	Working to improve support, services & raising awareness of unpaid carers in the UK	<p>Tel: 0300 772 9600</p> <p>Email: <a href="mailto:info@carers.org">info@carers.org</a></p> <p>Website: <a href="http://www.carers.org">www.carers.org</a></p>
Carers UK	Making life better for carers	<p>Tel: 0808 808 7777 (Lines open Monday to Friday, 9am – 6pm)</p> <p>Online form: <a href="https://www.carersuk.org/about-us/contact-us">https://www.carersuk.org/about-us/contact-us</a></p> <p>Website: <a href="http://www.carersuk.org">www.carersuk.org</a></p>
Cruse Bereavement Care	Helping with bereavement	<p>Tel: 0808 808 1677 (Lines open 9:30am–5pm Monday, 9:30am–8pm Tuesday–Thursday &amp; weekends 10am–2pm)</p> <p>Online chat: <a href="https://www.cruse.org.uk/get-help/crusechat/">https://www.cruse.org.uk/get-help/crusechat/</a></p> <p>Website: <a href="http://www.cruse.org.uk">www.cruse.org.uk</a></p>
Culture Dementia	Supporting carers and people	Tel: 0800 014 8682 (24 hour service)

# Signposting

<b>UK</b>	living with dementia amongst the African/ Caribbean community	Online advice: <a href="https://www.culturedementiauk.org/contact">https://www.culturedementiauk.org/contact</a> Website: <a href="https://www.culturedementiauk.org/">https://www.culturedementiauk.org/</a>
<b>Dementia UK</b>	Providing specialist dementia support including their Admiral Nurse service	Tel: 0800 888 6678 Email: <a href="mailto:helpline@dementiauk.org">helpline@dementiauk.org</a> Website: <a href="https://www.dementiauk.org/">https://www.dementiauk.org/</a>
<b>Dementia Engagement and Empowerment Project (DEEP)</b>	Group support for people with dementia	Tel: Rachel Niblock (UK Coordinator) 07720 538851 Email: <a href="mailto:niblock@myid.org.uk">niblock@myid.org.uk</a> Website: <a href="https://www.dementiavoices.org.uk/">https://www.dementiavoices.org.uk/</a>
<b>Dementia Shop</b>	Online shop & advice platform	Tel: 0207 377 2885 Email: <a href="mailto:dementiashop@stir.ac.uk">dementiashop@stir.ac.uk</a> Website: <a href="http://www.dementiashop.co.uk">http://www.dementiashop.co.uk</a>
<b>Independent Age</b>	Information & advice; support & campaigning	Tel: 0800 319 6789 & 0207 605 4200 Email: <a href="mailto:advice@independentage.org">advice@independentage.org</a> Website: <a href="https://www.independentage.org/">https://www.independentage.org/</a>
<b>Making Space</b>	Supporting people to live well with dementia	Tel: 01925 571 680 Online form: <a href="https://makingspace.co.uk/contact">https://makingspace.co.uk/contact</a>
		Website: <a href="https://makingspace.co.uk/services/dementia">https://makingspace.co.uk/services/dementia</a>
<b>NHS</b>	Online advice page	Website: <a href="https://www.nhs.uk/conditions/dementia/carers/">https://www.nhs.uk/conditions/dementia/carers/</a>
<b>Samaritans</b>	Emotional help for people having a difficult time & struggling to cope	Tel: 116 123 (free any time) Email: <a href="mailto:jo@samaritans.org">jo@samaritans.org</a> Website: <a href="https://www.samaritans.org/">https://www.samaritans.org/</a>
<b>Tide – together in dementia everyday</b>	Building a better future for carers of people with dementia	Tel: 0151 237 2669 Email: <a href="mailto:carers@tide.uk.net">carers@tide.uk.net</a> Website: <a href="https://www.tide.uk.net/">https://www.tide.uk.net/</a>
<b>University of Manchester Dementia Law Centre</b>	Legal written advice from supervised university students	Tel: 0161 275 7976 Email: <a href="mailto:free.legal@manchester.ac.uk">free.legal@manchester.ac.uk</a> Online form: <a href="https://www.socialsciences.manchester.ac.uk/legal-advice-centre/services/request-an-appointment/">https://www.socialsciences.manchester.ac.uk/legal-advice-centre/services/request-an-appointment/</a> Website: <a href="https://www.socialsciences.manchester.ac.uk/legal-advice-centre/">https://www.socialsciences.manchester.ac.uk/legal-advice-centre/</a>