

# Finance and young onset dementia



If you develop young onset dementia (where symptoms occur before the age of 65), it is natural to worry about how you will cope with financial and legal issues now and in the future. As a younger person, you may be working and have significant financial obligations such as a mortgage, credit card bills and loans. You may have children who are still financially dependent on you, and parents who rely on your support.

If you care for someone with young onset dementia, there may be an impact on your own finances – for example, you might have to reduce your hours at work to look after them.

But while managing financial and legal matters can be daunting, planning ahead and putting processes in place at an early stage can provide reassurance and minimise issues in the future.

### Employment

Some people with young onset dementia continue to work for a period of time, with adjustments to their role or working environment where necessary. Others may stop work sooner than they had planned. This may be a personal choice, but sometimes people with dementia feel pressured by their employer to give up their job.

For example, employers may wrongly assume that the changes in a person's behaviour, productivity or performance are intentional and controllable. As a result, they may start a performance management process and even terminate the person's employment.

However, dementia is classified in England, Wales and Scotland as a disability in the Equality Act 2010, and in the Disability Discrimination Act 1995 in Northern Ireland. This means people with dementia have legal protection from discrimination at work. You can read more



about this in our leaflet on employment and young onset dementia – see Sources of support on p14 for details.

You may choose to reduce your hours, change your role or stop work completely if you have young onset dementia or care for someone with the condition. While this may feel right for your situation, it could lead to a substantial drop in income and cause money worries. However, financial support may be available to help you at this time. We explain some of the support you may qualify for in the following pages of this leaflet.

### **Pensions and early retirement**

Some people with young onset dementia choose to take early retirement and start drawing their pension. This applies only to private or workplace payments – you cannot claim your State Pension until you reach State Pension age.

Accessing your pension early may ease some of the final pressures of stopping work, but it is important to note that it may affect your income or what benefits you are entitled to. This is because pension is treated as income for benefits purposes, so the amount of income-based benefits you receive (eg Personal Independence Payment and Universal Credit) may be reduced, or you may no longer qualify at all.

It is important to seek professional advice when weighing up your options regarding claiming your pension. If you have a company or private pension, this could be from your employer, pension provider or an independent pensions adviser – please see Sources of support on p19 for more information.

### **Protecting your State Pension if you reduce your working hours or stop work**

The State Pension age is gradually going up. You can check when you will qualify for your pension using the Government's online calculator at [gov.uk/state-pension-age](https://gov.uk/state-pension-age)

State Pension is dependent on having paid National Insurance for a total of 10 years. If you do not accrue 10 qualifying years – for example, if you have to stop work or your earnings fall below the National Insurance threshold because of a dementia diagnosis or caring responsibilities – your State Pension may be reduced, or you may not get any at all.

National Insurance credits can help prevent this situation. They are not a direct payment, but they help to fill in any gaps in your National Insurance record so your eligibility for a State Pension is not affected. You may get the credits automatically if you claim certain benefits, or you may have to apply for them. Please see Sources of support on p16 for more information.

## Benefits and grants

If you have a diagnosis of young onset dementia or care for someone who does, you may be eligible for benefits. These include:

**Access to Work grant:** a grant to help pay for practical, communication and mental health support at work and during interviews, enabling you to remain in work if you have a disability like dementia.

**Adult Disability Payment (Scotland):** a weekly benefit for adults with a disability or long-term health condition that affects daily living and/or mobility.

**Carer's Allowance:** a weekly benefit for people who care for someone for at least 35 hours a week.

**Council Tax reduction:** a discount on Council Tax if you have a long-term condition like dementia that impairs your cognitive functioning and are claiming certain other benefits; or if you are the only other adult living with someone who does.

**'New Style' Employment and Support Allowance:** a financial benefit to help with living costs if you are unable to work due to a disability or health condition, or to support you to get back into work.

**NHS continuing healthcare funding (CHC):** a package of care fully funded by the NHS for people with long-term, complex health needs that mean they require more support than Social Services can provide. Please see Sources of support on p15 for more information.

**Personal health budget:** an amount of money agreed between you/ your carer and the NHS which you can use to choose the healthcare and support that best suit you. It is available to adults who are receiving CHC, meet the eligibility criteria for the wheelchair service,

or qualify for section 117 aftercare after being detained under certain sections of the Mental Health Act.

**Personal Independence Payment (PIP):** a benefit to help with living costs if you have a long-term physical or mental health condition or disability that causes difficulty doing certain everyday tasks or getting around.

**Statutory Sick Pay (SSP):** a weekly payment for people who are too ill to work, paid by your employer for up to 28 weeks.

**Universal Credit:** a benefit to help with living costs if you are on a low income, out of work or unable to work. It is paid monthly (fortnightly or monthly in Scotland).

You can use a benefits calculator to find out which benefits you or the person you support might be entitled to – please see Sources of support on p17-19.

Organisations such as Age UK or Citizens Advice can also help if you need advice around benefits or support with completing application forms – please see Sources of support on p16-17 for details.

If you care for someone who needs assistance with applying for or managing benefits, you can apply to the Department of Work and Pensions to become their ‘appointee’. Appointeeship allows you to manage their benefits for them. Please see Sources of support on p15 for more information.

### Day-to-day financial management

It can be difficult to manage your finances when you are living with or caring for someone with dementia, especially if your income suddenly drops. In addition, dementia sometimes changes the way people behave with money – for example, they may gamble, spend impulsively, or purchase items that are not needed, including buying the same item repeatedly.





Here are some suggestions that may help you manage your everyday finances and avoid building up debt:

- Set up standing orders or direct debits for all your regular bills such as rent or mortgage, Council Tax, gas, electric and water
- Set a withdrawal limit on your bank accounts and reduce your credit limit on bank and credit cards
- If you have multiple bank accounts, consider consolidating them and closing the ones you no longer need so they are easier to manage
- Keep a record of your income and regular outgoings to limit overspending
- Consider signing up for online banking if you have not already – it can make it quicker and easier to check your account balance, make payments and keep track of transactions
- Prepaid cards can be a good idea for people on a budget or if you

want to limit your own spending or the spending of someone you care for, as you can only spend the balance uploaded to the card

- Joint bank accounts can be useful for couples where one person has dementia, as the other can monitor outgoings, but be aware that each person is liable for the other's debts. If a joint account holder loses capacity and you do not have lasting power of attorney in place (see p10), the bank may restrict the account to essential transactions only
- Keeping your money separate in personal accounts can be beneficial for things other than essential joint bills. If one of you receives benefits or requires paid care, your local council will means-test only the person who is receiving the service, not both of you
- If you do not feel able to manage your finances, consider asking someone you trust to help

If you are worried about your finances, consider getting professional advice as soon as possible. Do not ignore letters if you get into difficulties: contact the company, explain your circumstances and seek advice, or ask someone you trust to do this for you.

If you have investments or need help around financial planning, we recommend seeking advice from a qualified financial adviser who is regulated and authorised by the Financial Conduct Authority: visit [fca.org.uk](https://www.fca.org.uk)

For more details of services and organisations that offer financial advice and support, see Sources of support on p16-19.

### Scams

Dementia often impairs people's judgement and decision-making, which makes them vulnerable to scams – on the doorstep, by email,





by phone or text, and on social media. These tips will help protect you from scammers.

- Contact your mobile or landline provider to enquire if they have a service that can block suspicious or unknown numbers to avoid scams
- Register with the Mailing Preference Service and Telephone Preference Service to stop unsolicited mail, mobile and landline calls – see Sources of support on p18-19
- Do not click on any links in emails, texts, WhatsApp messages or other social media messaging apps from senders you do not recognise; and do not respond to requests to send money or your bank details
- Be aware that scammers may impersonate someone you know – if you receive an unusual request, for example for money, check with the person that it is genuine
- Take extra care if you are considering making an online purchase

from a retailer you do not recognise – look up reviews on a reliable reviews site first

- Always ask for identification if someone knocks on your door and never let anyone you do not know into your home – you might want to display a ‘No cold callers’ sticker
- Consider joining your local Neighbourhood Watch as they will often send emails notifying members of the latest scams
- Be aware that banks and building societies will never ask you for your account details by phone, text or email

## Legal matters

### Lasting power of attorney

Lasting power of attorney (LPA) is a legal process where you appoint someone (known as your ‘attorney’) to make decisions for you if you lack the mental capacity to do so yourself. There are two types, and you can make either or both:

- health and welfare – for decisions about health and personal welfare, such as where you might live, your day-to-day care or medical treatment
- property and financial affairs – for decisions about finances, such as selling your house or managing your money

After a diagnosis of young onset dementia, it is advisable to make an LPA as soon as possible. You should choose someone to be your attorney who knows you well, and who you trust to act in your best interests and reflect your views, choices and wishes. You can have more than one attorney.

You can set up an LPA yourself using a form from the Office of the Public Guardian (OPG): please see Sources of support on p19 for details. Alternatively, you can ask a solicitor to set it up for you.



Before you can use an LPA, you must send it to the OPG to be registered. This can take up to 20 weeks. A property and financial affairs LPA can be used by the attorney as soon as it is registered, with your permission. A health and welfare LPA can only be used by your attorney once you can no longer make your own decisions.

In Scotland, LPA is known as power of attorney. In Northern Ireland, it is called enduring power of attorney and only covers property and financial affairs, not health and welfare.

For more information on all three types of power of attorney and mental capacity, see Sources of support on 17-19.

### **Deputyship under the Court of Protection**

If you care for someone with dementia who lacks the mental capacity to make decisions for themselves and has not made an LPA, the Court of Protection may appoint you as the person's 'deputy' and give you permission to make one-off or ongoing decisions on their behalf.

You can be a deputy for matters relating to:

- property and financial affairs
- personal welfare

It is important to note that applying to become a deputy can be a difficult process that involves filling out a number of forms and paying a fee, so it is always preferable to make an LPA as soon as possible after a dementia diagnosis.

To find out more about becoming a deputy, please see Sources of support on p17.

### **Making a Will**

A Will ensures that your money and possessions are left to the people or causes of your choosing after your death. Every adult should have one regardless of their current state of health. If you do not have a Will and have been diagnosed with dementia, you should make one as soon as possible.

Although you can write your own Will, it is recommended that you seek legal advice from a solicitor or Will-writer to make sure your wishes are interpreted in the way you want. This is especially important if your Will is not straightforward, for example if:

- you share a property with someone who is not your husband, wife or civil partner
- you want to leave money or property to a dependant who cannot care for themselves
- you have several family members who may make a claim on your Will, for example, a former spouse or children from another marriage
- you have a business



Your Will must be formally witnessed and signed to make it legally valid.

If you already have a Will and have been diagnosed with dementia, it is advisable to review it to make sure it reflects the changes in your circumstances and your current wishes. If you want to update it at any point, you need to make an official alteration called a codicil or make a new Will.

For more information on making a Will, including free Will-writing offers from Dementia UK, please see Sources of support on p14 and p18.

## Sources of support

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To speak to a dementia specialist Admiral Nurse about financial and legal issues or any other aspect of dementia, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email

➤ [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can pre-book a phone or video call appointment with an Admiral Nurse: visit ➤ [dementiauk.org/book](https://dementiauk.org/book)

### Dementia UK information

#### Young onset dementia section

➤ [dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

#### Capacity and decision-making

➤ [dementiauk.org/capacity-decision-making](https://dementiauk.org/capacity-decision-making)

#### Council Tax discount for people with dementia

➤ [dementiauk.org/council-tax-discount-for-people-living-with-dementia](https://dementiauk.org/council-tax-discount-for-people-living-with-dementia)

#### Employment and young onset dementia

➤ [dementiauk.org/employment-and-young-onset-dementia](https://dementiauk.org/employment-and-young-onset-dementia)

#### Free Will-writing offers

➤ [dementiauk.org/freewill](https://dementiauk.org/freewill)

#### Financial and legal sources of support and advice

➤ [dementiauk.org/financial-and-legal-sources-of-support](https://dementiauk.org/financial-and-legal-sources-of-support)

#### Guide to NHS continuing healthcare (CHC)

➤ [dementiauk.org/guide-to-continuing-healthcare-funding](https://dementiauk.org/guide-to-continuing-healthcare-funding)

### **Lasting power of attorney**

➤ [dementiauk.org/lasting-power-of-attorney](https://dementiauk.org/lasting-power-of-attorney)

## **Benefits information**

### **General information on benefits and grants**

**England and Wales:** ➤ [gov.uk/browse/benefits](https://gov.uk/browse/benefits)

**Scotland:** ➤ [mygov.scot/browse/benefits](https://mygov.scot/browse/benefits)

**Northern Ireland:** ➤ [nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support](https://nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support)

### **Access to Work grant**

➤ [gov.uk/access-to-work](https://gov.uk/access-to-work) **(England, Wales and Scotland)**

➤ [nidirect.gov.uk/articles/access-work-practical-help-work](https://nidirect.gov.uk/articles/access-work-practical-help-work)  
**(Northern Ireland)**

### **Adult Disability Payment (Scotland)**

➤ [mygov.scot/adult-disability-payment](https://mygov.scot/adult-disability-payment)

### **Appointeeship**

➤ [gov.uk/become-appointee-for-someone-claiming-benefits](https://gov.uk/become-appointee-for-someone-claiming-benefits)

### **Carer's Allowance**

➤ [gov.uk/carers-allowance](https://gov.uk/carers-allowance)

### **Council Tax discounts for disabled people**

➤ [gov.uk/council-tax/discounts-for-disabled-people](https://gov.uk/council-tax/discounts-for-disabled-people)

### **Employment and Support Allowance (ESA)**

➤ [gov.uk/employment-support-allowance](https://gov.uk/employment-support-allowance)

### **National Insurance credits**

➤ [gov.uk/national-insurance-credits](https://gov.uk/national-insurance-credits)



### **NHS continuing healthcare funding**

➤ [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare](https://nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare)

### **Personal health budgets**

➤ [nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget](https://nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget)

### **Personal Independence Payment (PIP)**

➤ [gov.uk/pip](https://gov.uk/pip)

### **State Pension age checker**

➤ [gov.uk/state-pension-age](https://gov.uk/state-pension-age)

### **Statutory Sick Pay (SSP)**

➤ [gov.uk/statutory-sick-pay](https://gov.uk/statutory-sick-pay)

### **Universal Credit**

➤ [gov.uk/universal-credit](https://gov.uk/universal-credit)

## **Other resources**

### **Acas**

Free, impartial advice on workplace rights, rules and best practice

➤ [acas.org.uk](https://acas.org.uk)

### **Action Fraud**

➤ [actionfraud.police.uk](https://actionfraud.police.uk)

### **Age UK**

Information, advice and advocacy to people over 50. Includes Age Scotland, Age Cymru and Age NI

➤ [ageuk.org.uk](https://ageuk.org.uk)



### **BeGambleAware**

Free, confidential support around gambling

➤ [begambleaware.org](https://begambleaware.org)

### **Citizens Advice**

➤ [citizensadvice.org.uk](https://citizensadvice.org.uk)

### **Deputies: make decisions for someone who lacks capacity**

➤ [gov.uk/become-deputy](https://gov.uk/become-deputy)

### **Early retirement, pensions and benefits**

➤ [gov.uk/early-retirement-pension/benefits](https://gov.uk/early-retirement-pension/benefits)

### **Enduring power of attorney (Northern Ireland)**

➤ [nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney](https://nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney)

### **entitledto benefits calculator**

➤ [entitledto.co.uk/benefits-calculator](https://entitledto.co.uk/benefits-calculator)

### **Equality Advice and Support Service**

Advice on equality and human rights

➤ [equalityadvisoryservice.com](https://equalityadvisoryservice.com)

### **Lasting power of attorney (England and Wales)**

➤ [gov.uk/power-of-attorney](https://gov.uk/power-of-attorney)

### **The Law Society: find a solicitor**

➤ [solicitors.lawsociety.org.uk](https://solicitors.lawsociety.org.uk)

### **Mailing Preference Service**

Free service to remove home addresses from mailing lists

➤ [mpsonline.org.uk](https://mpsonline.org.uk)

### **Making a Will**

➤ [gov.uk/make-will](https://gov.uk/make-will)

### **Money Helper**

Free impartial advice on benefits, debt, and finances

➤ [moneyhelper.org.uk](https://moneyhelper.org.uk)

### **Money Saving Expert**

Consumer finance and money saving advice

➤ [moneysavingexpert.com](https://moneysavingexpert.com)

### **National Debtline**

Free, independent debt advice

➤ [nationaldebtline.org](https://nationaldebtline.org)

### **Neighbourhood Watch**

➤ [ourwatch.org.uk](https://ourwatch.org.uk)

**Office of the Public Guardian**

➤ [gov.uk/government/organisations/office-of-the-public-guardian](https://gov.uk/government/organisations/office-of-the-public-guardian)

**Pathways Through Dementia**

Free legal and financial information for people living with dementia

➤ [pathwaysthroughdementia.org](https://pathwaysthroughdementia.org)

**Personal Finance Society: find a financial adviser**

➤ [thepfs.org/yourmoney/find-an-adviser](https://thepfs.org/yourmoney/find-an-adviser)

**Power of attorney (Scotland)**

➤ [mygov.scot/power-of-attorney](https://mygov.scot/power-of-attorney)

**Telephone Preference Service**

Opt out of unsolicited phone calls

➤ [tpsonline.org.uk](https://tpsonline.org.uk)

**The Law Society**

Database of independent professional solicitors

➤ [solicitors.lawsociety.org.uk](https://solicitors.lawsociety.org.uk)

**Turn2us**

Practical support for people who are struggling financially

➤ [turn2us.org.uk](https://turn2us.org.uk)

**Turn2us benefits calculator**

➤ [benefits-calculator.turn2us.org.uk](https://benefits-calculator.turn2us.org.uk)

**Unbiased**

Find an independent pensions adviser

➤ [unbiased.co.uk](https://unbiased.co.uk)

**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:  
**0800 888 6678 or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)**

Book a virtual appointment:  
**[dementiauk.org/book](https://dementiauk.org/book)**

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit **[dementiauk.org/donate](https://dementiauk.org/donate)**
- Scan the QR code

**Thank you.**



**dementiauk.org • [info@dementiauk.org](mailto:info@dementiauk.org)**

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