



DementiaUK
Helping families face dementia

Finance and young onset dementia



If you are diagnosed with young onset dementia (where symptoms develop 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 avoid issues later on.

Employment

Some people with young onset dementia continue to work with

adjustments to their workplace or role, but 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 a person with a dementia diagnosis has 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 p10 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 who has. 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.

Pensions and early retirement

Some people with young onset dementia choose to take early retirement and start drawing their pension. But accessing your pension early may affect your income or what benefits you are entitled to.

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.

For more information, visit [gov.uk/early-retirement-pension/benefits](https://www.gov.uk/early-retirement-pension/benefits), or to find an independent pensions adviser, visit [unbiased.co.uk](https://www.unbiased.co.uk) or [thepfs.org/yourmoney/find-an-adviser](https://www.thepfs.org/yourmoney/find-an-adviser)

Protecting your State Pension

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://www.gov.uk/state-pension-age)

If you have to stop work before you reach the State Pension age because you have dementia or take on a caring role, you can protect your pension entitlement with National Insurance credits. These help to fill in any gaps in your National Insurance record.

You may get the credits automatically or you may have to apply for them. To find out more, visit [gov.uk/national-insurance-credits](https://www.gov.uk/national-insurance-credits)

Benefits and grants

If you have a diagnosis of young onset dementia or care for someone who does, you may be eligible for benefits, particularly if you are no longer able to work. These include:

Access to Work grant

A grant to help pay for practical, communication and mental health support at work and during interviews.

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 'severe mental impairment' like dementia and claim certain other benefits, or if you are the only other adult living with someone who does.

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 funding for some people with long-term complex health needs to help with their care needs. See Sources of support on p10 for our information on CHC.

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.

Personal Independence Payment

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

A weekly payment for people who are too ill to work, paid by your employer for up to 28 weeks.

Universal Credit

A monthly (fortnightly in Scotland) benefit to help with living costs if you are on a low income, out of work or unable to work.

You can use a benefits calculator to find out which benefits you or the person you support might be entitled to: visit [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)

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 p10.

Appointeeship

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. This allows you to manage their benefits for them. To find out more visit [gov.uk/become-appointee-for-someone-claiming-benefits](https://www.gov.uk/become-appointee-for-someone-claiming-benefits)

Day-to-day financial management

It can be difficult to manage your finances, 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 multiple items that are not needed.

Some people also find themselves vulnerable to internet and telephone marketing sales and scams.

Here are some suggestions that may help you manage your finances on a daily basis 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 closing some so they are easier to manage
- Keep a record of your income and regular outgoings to limit overspending
- Consider signing up for online banking – 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 choice for people on a budget or if you want to keep an eye on a person’s spending, as you can only spend the balance uploaded to the card
- Joint bank accounts can be useful 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 p7), 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 applies for a Personal Budget or requires paid care, your local authority 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

Some additional things to consider:

- 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 p11
- Always ask for identification if someone knocks on your door and never let anyone you do not know into your home

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 p11.

Legal matters

Lasting power of attorney

Lasting power of attorney 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 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 who knows you well, and who you trust to act in your best interests and reflect your views, choices and wishes.

You can set up LPA yourself using a form from the Office of the Public Guardian (OPG): visit gov.uk/power-of-attorney/make-lasting-power. Alternatively, you can ask a solicitor to set it up for you.

Before you can use your LPA, you must send it to the OPG, who will register it. This can take up to 20 weeks.

A property or affairs LPA can be used by your 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.

For more information on LPA and mental capacity, see Sources of support on p10.

Deputyship under the Court of Protection

If you care for someone with dementia who lacks the mental capacity to make decisions for themselves, but you don't have 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 affairs
- personal welfare

To find out more about what the Court of Protection does, visit gov.uk/courts-tribunals/court-of-protection. For information about becoming a deputy, visit gov.uk/become-deputy

Making a Will

A Will ensures that your money and possessions are left to the people or charities of your choosing after your death, and every adult should have one.

If you don't 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 eg 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, visit dementiauk.org/freewill or gov.uk/make-will. To find a solicitor, visit solicitors.lawsociety.org.uk

Sources of support

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

If you prefer, you can book a phone or video appointment at a time to suit you at dementiauk.org/get-support/closer-to-home

Dementia UK information

Young onset dementia section
dementiauk.org/young-onset-dementia

Employment and young onset dementia
dementiauk.org/employment-and-young-onset-dementia

Financial and legal sources of support and advice
dementiauk.org/sources-of-support-and-advice

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Guide to NHS continuing healthcare (CHC)
dementiauk.org/guide-to-continuing-healthcare-funding

Capacity and decision-making
dementiauk.org/capacity-decision-making

Other resources

Access to Work grant
gov.uk/access-to-work
(England, Wales and Scotland)
nidirect.gov.uk/articles/access-work-practical-help-work (Northern Ireland)

Acas
Free, impartial advice on workplace rights, rules and best practice
acas.org.uk

Age UK
Information, advice and advocacy to people over 50. Includes Age Scotland, Age Cymru and Age NI
ageuk.org.uk

BeGambleAware

Free, confidential support around gambling

begambleaware.org

Benefits and grants

gov.uk/browse/benefits

(England and Wales)

mygov.scot/browse/benefits

(Scotland)

nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support (Northern Ireland)

Citizens Advice

citizensadvice.org.uk

Equality Advice and Support Service

Advice on equality and human rights

equalityadvisoryservice.com

Mailing Preference Service

Free service to remove home addresses from mailing lists

mpsonline.org.uk

Money Helper

Free impartial advice on benefits, debt, and finances

moneyhelper.org.uk/en

National Debtline

Free, independent debt advice

nationaldebtline.org

Money Saving Expert

Consumer finance and money saving advice

moneysavingexpert.com

Office of the Public Guardian

Information on lasting power of attorney

gov.uk/government/organisations/office-of-the-public-guardian

Pathways Through Dementia

Free legal and financial information for people living with dementia

pathwaysthroughdementia.org

Solicitors for the Elderly

Legal advice for vulnerable people including people with dementia and their families

sfe.legal

Telephone Preference Service

Opt out of unsolicited phone calls

tpsonline.org.uk

The Law Society

Database of independent professional solicitors

solicitors.lawsociety.org.uk

Turn2us

Practical support for people who are struggling financially

turn2us.org.uk

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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