

Employment and young onset dementia



What is young onset dementia?

Dementia is described as ‘young onset’ when symptoms develop before the age of 65. It affects around 70,800 people in the UK.

Younger people with dementia face a different set of challenges from people who develop the condition later in life. One such challenge is their ability to work.

Why is employment important?

Having a job is not just about earning money. It can also provide people with purpose, a daily routine, satisfaction, and a sense of normality. It often helps people gain or maintain self-esteem, and many benefit from the relationships and connections formed through work. All of these factors can have a significant effect on their wellbeing.

How might young onset dementia affect employment?

People with young onset dementia often have a very different experience from older people with the condition. This is partly due to being at a stage of life where in most cases, people are able to have active and productive work, family and social lives.

People with young onset dementia often have:

- a job or career
- financial commitments, like rent/mortgage and building a pension
- dependent children and/or ageing parents who need support
- a partner whose own ability to work may be affected by their caring role



Dementia is a progressive, life-limiting condition, so while initially, a person with young onset dementia may be able to continue to work with the right support, they will eventually start to find it more challenging or overwhelming, leading to them ending their working life earlier than planned.

People in the early stages of young onset dementia may:

- have difficulties with concentration and orientation
- make uncharacteristic mistakes at work
- have problems with communication, such as finding the right words
- struggle with literacy and numeracy
- experience changes in personality and behaviour that affect their work, eg reacting with frustration or anger if tasks do not go to plan

These issues may make work feel more difficult and result in distress, embarrassment, and a loss of confidence.

Employers may wrongly assume that these changes are intentional or controllable – for example, that the person is being lazy if they do not complete tasks on time. As a result, they may start a performance management process, and in some cases, even terminate the person's employment.

Work colleagues may be the first to recognise the early changes associated with young onset dementia, but they might attribute them to another cause such as stress, tiredness, relationship issues or physical or mental ill health. Family members may recognise that the person is struggling at work, but not understand why.

An added complication is that younger people are more likely to have a rarer form of dementia that has different symptoms from the more common types and so is harder to recognise – for example, changes in their personality, behaviour and social functioning, rather than memory.

Employment rights and young onset dementia

A lack of recognition of the early signs of young onset dementia often means that it takes longer for younger people to get a diagnosis. This can lead to a delay in them using their employment rights, accessing appropriate support at work, and ultimately leaving their job with dignity, with all legal protections and benefits intact.

Dementia is classified as a disability in the Equality Act 2010 in England, Wales and Scotland, and in the Disability Discrimination Act 1995 in Northern Ireland. This means a person with dementia is legally protected from discrimination – including being pushed towards early retirement or facing formal dismissal due to their diagnosis.

To ensure these rights are recognised, it is advisable (although not a legal obligation in the majority of jobs) for the person to talk to their employer soon after their diagnosis. If they feel uncomfortable talking to their immediate manager, they can raise the issue with the Human Resources (HR) Manager. It may be helpful to do this with the support of a colleague or family member.

The employer should then refer the person to an occupational health service to discuss and assess the specialist advice and support they may need to help them continue to work.

In some occupations, there is a legal requirement for a person with dementia to disclose their diagnosis. These include the armed forces, healthcare professionals, people operating dangerous machinery, and people for whom driving is an essential part of the job. To be certain, the person should read their employment contract and speak to their employer's HR Team.

If a person believes they are being discriminated against because they have dementia, they should first talk to their employer or HR Manager to try to resolve the issue informally. It is advisable to put concerns in writing.

All employers should have a written complaints policy. If the issue cannot be resolved informally, the person should follow the steps in the policy to escalate their complaint. It may help to use a mediator or advocate at this stage.

If the outcome is still unsatisfactory, the person may be able to take their complaint to an employment tribunal. The organisation Acas can help with this – please see Sources of support on page 10 for information.

Adjustments in the workplace for people with young onset dementia

After an occupational health assessment, the service should devise an employment action plan, with the full involvement of the person with dementia. This should include an evaluation of their current workload, taking into consideration how dementia affects their ability to do their job.

It is important for the person with dementia to be honest about how it affects their work – the employer has a duty to help.

Decisions relating to how the person can be supported will depend on their unique situation, but some of the reasonable adjustments that the occupational health service may suggest and implement include:

- allocating tasks individually, rather than all at once
- giving advice on simplifying routines
- providing a quieter workspace with fewer distractions
- enabling supported homeworking
- offering regular rest breaks during the day
- providing assistive technology eg alerts, reminders, voice recognition software
- setting up a buddy scheme and regular support sessions
- a reduction in hours (if needed or requested)
- a move to a role with less responsibility (if needed or requested)

It may be helpful for the person to tell their colleagues – often, they will be supportive and understanding.

Working while caring for a person with young onset dementia

Partners or family members of a person living with dementia often have to change their working patterns or leave their job altogether due to their caring role. This may have consequences for their financial stability, mental health and wellbeing – and further into the future, it may be difficult for them to return to work after taking a break.

If possible, it is helpful for the person with caring responsibilities to tell their employer about their situation so they can put support and accommodations in place, for example allowing them to leave work early to take the person with dementia to an appointment.

Flexible working patterns often allow carers to continue to work while looking after someone with dementia. The Flexible Working Regulations 2014 require employers to consider these requests. To qualify for consideration for flexible working, a person must:

- have been working for the employer for at least 26 weeks
- submit the request in writing
- state whether there has been a previous application for flexible working, and if so, the date of that application – by law, people have the right to apply once a year, but many employers will consider another request if circumstances change

Everyone is entitled to ‘time off work for family and dependants’, for example if there is an emergency with the person they care for. There is no fixed amount of time for this, as long as it is ‘reasonable’, and there is no limit to how many times it is taken, although the employer may request a meeting if they think the time off is affecting the person’s work. It does not have to be paid.

It is a good idea for people with caring responsibilities to apply for a carer's assessment from social services – this looks at how their needs as a carer can be met, eg with respite care or accessing benefits – please see Sources of support on p10.

Alternative occupations and meaningful activities

Adjusting to new working patterns – or stopping work altogether – can be very difficult for a person with young onset dementia. Finding an alternative occupation or meaningful activity is important for maintaining wellbeing, giving a sense of purpose and routine, keeping socially connected and lifting mood and energy levels.

This is especially true if the person chooses the activity themselves and finds it rewarding. They may even now have time to fulfil a long-held ambition or follow up a new idea. This could involve:

- part-time employment either in the same field or a different one that utilises their knowledge and skills
- volunteering
- creative activities eg art, photography, singing
- sport activities eg walking, running, swimming
- further study or classes
- campaigning
- research
- travel and exploring

Social prescribing may also be helpful. A trained professional – often known as a link worker – can connect people to activities, groups, and services in their local community that will support their practical, social and emotional needs, improving their health and wellbeing.



Referrals can be made by a variety of services, including GPs, social services, hospitals and voluntary organisations.

Keep in mind that the person's needs will change over time and be prepared to adapt as necessary.

Self-employment and young onset dementia

A diagnosis of dementia can have a big impact on a person who is self-employed. They may have to reduce their workload (perhaps taking on fewer projects or clients), allow extra time to complete tasks, make adaptations to their workspace (such as assistive technology), and eventually stop work altogether.

People who are self-employed and have a diagnosis of dementia may be able to claim certain benefits. These include:

- Employment Support Allowance (ESA)
- Personal Independence Payment (PIP)
- Universal Credit
- Disabled Facilities Grant

For more information on benefits and grants, please see p10 for details of our leaflet on Finance and young onset dementia.

Sources of support

To speak to a dementia specialist Admiral Nurse about employment and young onset dementia or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am–9pm, Saturday and Sunday 9am–5pm) or email

➤ helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit ➤ dementiauk.org/book

Dementia UK resources

Dementia UK young onset dementia section

➤ dementiauk.org/young-onset-dementia

The carer's assessment

➤ dementiauk.org/the-carers-assessment

Finance and young onset dementia

➤ dementiauk.org/finance-and-young-onset-dementia

Understanding and challenging stigma and discrimination

➤ dementiauk.org/dealing-with-stigma

Other resources

Acas

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

➤ acas.org.uk

Access to Work grant

➤ gov.uk/access-to-work (England, Wales and Scotland)

➤ nidirect.gov.uk/articles/access-work-practical-help-work
(Northern Ireland)

Benefits calculators

➤ gov.uk/benefits-calculators

Citizens Advice

Free, confidential advice on issues including employment

➤ citizensadvice.org.uk

Equality Advice and Support Service (EASS)

Advice on equality and human rights

➤ equalityadvisoryservice.com

IPSE

Support for self-employed people and freelancers

➤ ipse.co.uk

Pathways Through Dementia

Free legal and financial information to support people living with dementia

➤ pathwaysthroughdementia.org

Turn2Us

Advice on accessing benefits, grants and other financial support

➤ turn2us.org.uk

Young Dementia Network

An online influencing community of people affected by young onset dementia, their family and friends, and professionals working in the field

➤ youngdementianetwork.org

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

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
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**
- Scan the QR code

Thank you.



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Publication date: January 2024. Review date: January 2027. © Dementia UK 2024

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