

Employment and young onset dementia



What is young onset dementia?

Dementia is described as ‘young onset’ when symptoms develop before the age of 65. An estimated 70,800 of the estimated 944,000 people living with dementia in the UK are living with young onset dementia.

Younger people with dementia face a different set of challenges to 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. People also gain self-esteem, and 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 who develop young onset dementia often have a very

different experience from older people with the condition. This is partly due to their stage of life, where they are expected to be active and productive in their work, family and social lives.

People with young onset dementia often have:

- a commitment to a job or career
- financial commitments, like rent/mortgage, and building a pension
- dependent children
- a partner who is also in employment, and whose ability to work is affected by their caring role

Dementia is a progressive, long-term condition, and over time, it can affect people’s ability to do their job. Initially, they may be able to continue to work with the right support – but as the condition advances, they may start to find work more challenging or overwhelming. This may eventually lead to them ending their working life earlier than planned.



Recognising the signs of young onset dementia in the workplace

People in the early stages of young onset dementia may have difficulties with concentration and orientation. They may make uncharacteristic mistakes at work. There may be problems with communication, such as finding the right words, and simple work tasks may feel more difficult. This may result in distress, embarrassment, and a loss of confidence.

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 issue is that younger people have a greater likelihood of having a rarer form of dementia that has different symptoms from the more common types – for example, changes to their personality, behaviour, and social functioning, rather than memory.

Employers may wrongly assume that these changes are intentional or controllable. As a result, they may start a performance management process, and in some cases, even terminate the person's employment.

Employment rights and young onset dementia

A lack of recognition of the early signs of young onset dementia often leads to delays in diagnosis – and this can lead to a delay in people using their employment rights, accessing appropriate support at work, and ultimately leaving their job with dignity, and with all legal protections and benefits intact.

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 a legal protection from discrimination – including from being pushed towards taking early retirement or facing formal dismissal due to their diagnosis.

To ensure these rights are recognised, it's advisable (although not a legal obligation) 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 Manager.

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.

If a person believes they are being discriminated against because of their dementia, they should first talk to their employer or Human Resources Manager to try to resolve the issue informally. It can be helpful to put their 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 – see Sources of support on page 9 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 examination of their current workload, taking into consideration how dementia affects their ability to do their job.

It is helpful for the person with dementia to be open and honest about how their condition affects their work – the employer has a duty to help.

Decisions relating to how the person can be supported are individual and will depend on the person's abilities and situation, the employer and working environment.

Some of the reasonable

adjustments that Occupational Health 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 with the diagnosis to tell immediate colleagues, as this may lead to them being more understanding and supportive.

Some occupations have a legal requirement that a person with dementia discloses 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 Human Resources Team. It may be useful to do this with the support of a colleague or family member.

Employment 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 employment altogether due to their caring responsibilities. This may have consequences for their financial stability, mental health and wellbeing – and further into the future, it can be difficult for family members to resume their working lives after taking a break.

Flexible working patterns often

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 these, and other benefits and grants that the person may be able to claim, see our leaflet [Getting financial help and support at dementiauk.org/financial-help](https://dementiauk.org/financial-help)

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

Alternative occupations and meaningful activities

If the person with dementia has reduced or stopped work, finding an alternative occupation or meaningful activity is important for maintaining wellbeing, giving a sense of purpose and routine, and lifting mood and energy levels.

This is especially true if the person has chosen 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

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

“I wanted to leave work on my terms when I felt ready. I was offered early retirement from teaching. It had been a job I’d done for 32 years.”

Keith, diagnosed at 55 with young onset Alzheimer’s disease

“When I was diagnosed, I was working for a computer company and had a very responsible job. I went onto light duties but after a while I couldn’t manage those either and I was made redundant.”

Larry, diagnosed with young onset dementia following a stroke

“I would have retired in another five years, but after my diagnosis I decided to stop work. It has had a massive impact on us financially. My wife and I are both self-employed and we have school and university fees to pay.”

Des, diagnosed with Lewy body dementia aged 60

“A year or so after my husband’s diagnosis, I asked my boss if I could reduce my days to four which enabled me to attend peer support meetings with my husband.”

Sarah, family member

Sources of support

Adjusting to new working patterns – or stopping work altogether – after a diagnosis of dementia can be very difficult. Our dementia specialist Admiral Nurses are here to offer support and advice.

Call our free Dementia 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 an appointment by phone or video call at a time to suit you at

dementiauk.org/get-support/closer-to-home

You might also find these resources and organisations helpful:

Dementia UK young onset dementia section

dementiauk.org/young-onset-dementia

Dementia UK leaflet on Understanding and challenging stigma and discrimination

dementiauk.org/dealing-with-stigma

Dementia UK leaflet on Getting financial help and support

dementiauk.org/financial-help

Dementia UK Adapt film - Employment and keeping active - features people living with young onset dementia and their family members

dementiauk.org/adapt-films

Acas

Free, impartial advice on workplace rights, rules and best practice
[acas.org.uk](https://www.acas.org.uk)

Access to Work grant

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

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

Benefits calculators

[gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)

Citizens Advice

Free, confidential advice on issues including employment
citizensadvice.org.uk

Employment Support Allowance (ESA)

[gov.uk/employment-support-allowance](https://www.gov.uk/employment-support-allowance)
(England, Wales and Scotland)

[nidirect.gov.uk/articles/employment-and-support-allowance](https://www.nidirect.gov.uk/articles/employment-and-support-allowance)
(Northern Ireland)

Equality Advice and Support Service (EASS)

Advice on equality and human rights
equalityadvisoryservice.com/app/home

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

Personal Independence Payment (PIP)

gov.uk/pip (England, Wales and Scotland)

nidirect.gov.uk/articles/personal-independence-payment-pip
(Northern Ireland)

Turn2Us

Advice on accessing benefits, grants and other financial support

turn2us.org.uk

Universal Credit

gov.uk/universal-credit (England, Wales and Scotland)

nidirect.gov.uk/universal-credit (Northern Ireland)

Young Dementia Network

The Young Dementia Network is a collaboration between people affected by and working in the field of young onset dementia

youngdementianetwork.org

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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