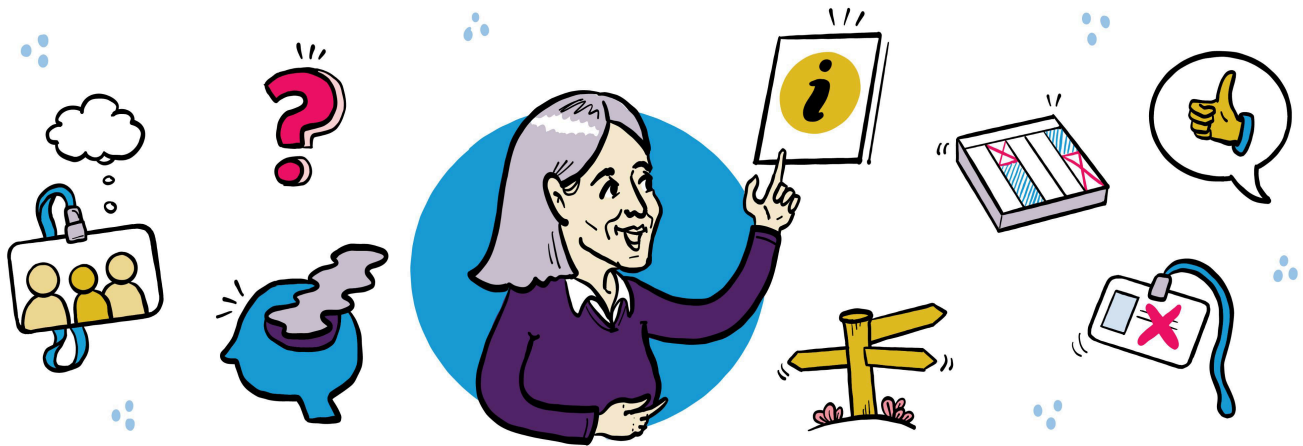


Working with Dementia Network Plus

How can we improve the work-related experiences of people living with dementia and family carers?



Project Summary

Why did we do this study?

Dementia in the workplace is increasingly recognised as a global issue. In the UK, around 850,000 people live with dementia and about 7.5% are under 65, meaning many will experience symptoms while still working. Although research shows that continued employment after diagnosis is possible, there's little guidance on how to make this happen in practice. To better understand what matters most to people living with dementia, we invited a range of people to take part in a focus group.

How did we do it?

During September and October 2025 we organised seven focus groups. Each group was for participants offering different perspectives:

- Group 1 and Group 2: Participants with a dementia diagnosis (13 participants in total)
- Group 3 and Group 4: Participants with experience of caring for a loved one with dementia (14 participants in total)
- Group 5: Participants with experience as employers or managers of employees (5 participants)
- Group 6: Participants with a professional role in policy making and development (5 participants)
- Group 7: Participants with professional roles in academia or research (10 participants)

We used a focus group method called Nominal Group Technique (NGT). In each group everyone shared their ideas individually, then discussed them together before anonymously ranking them in order of importance. We looked at the results together and had a final discussion.



Each group was asked the same question:

‘From your own perspective, what are the most important things that need to happen to improve the work-related experiences of people living with dementia and family carers?’

The shortlisting and phrasing of ideas was determined by participants in each group. Here are the top ideas from each group, in the order they were ranked by group participants:

Group 1 (Participants living with a dementia diagnosis)

- 1 The focus must be on the person’s ability and wellbeing rather than disability (as with other long-term conditions).**
- 2 Government guidance and policy for employers (for example; clear expectations that apply throughout the UK and throughout organisational hierarchies).**
- 3 Assessment for capability for current role as an individual rather than a dementia diagnosis, including flexibility and reasonable adjustments (such as travel time and hours worked).**
- 4 Improve the education about existing legislation to protect the workplace rights for those living with dementia.**
- 5 Continuing assessment of workplace adaptation and potential redeployment or alternative use of skillset (as is generally expected with other conditions).**

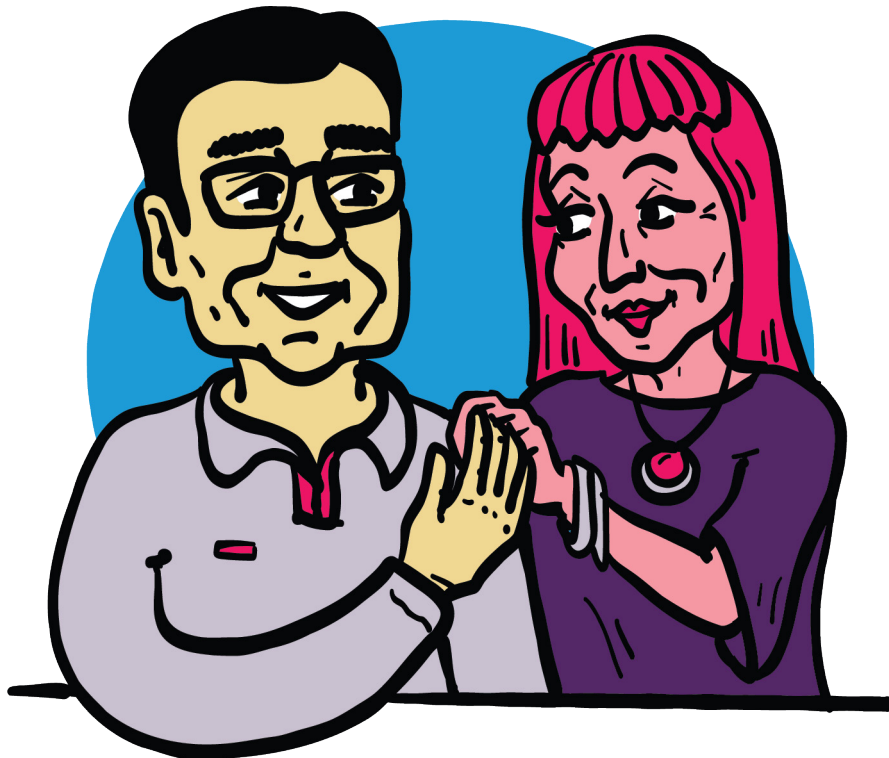
Group 2 (Participants living with a dementia diagnosis)

- 1 Provide workplace adjustments, accommodation, and must include collaboration and flexibility**
- 2 Individualised support for all different employment contexts**
- 3 Recognise strengths and personhood while addressing weaknesses and always remembering we are all different**
- 4 Commitment for company-wide education and awareness to reduce stigma and promote social inclusion for those living with dementia.**



Group 3 (Participants with experience as informal carers)

- 1 Early and accurate diagnosis, with support to enable timely diagnosis (gateway access to benefits and support - for carers and people with dementia)
- 2 Education and training about dementia in the workplace to improve attitudes, behaviours, responses to early symptoms and address stigma
- 3 (=) Recognition of impact of losing a career on mental health, wellbeing, finances and social interaction
- 4 (=) Recognising the challenges of the caring role, make allowances and the importance of support available to allow carers to continue working
- 5 Understanding continued employment won't always be possible (can include safety of individual and others)
- 6 Workplace flexibility, adjustment and support (including working from home and flexible hours for carers and people with dementia)



Group 4 (Participants with experience as informal carers)

- 1 Flexible working arrangements for carer and person with dementia
- 2 Mandatory and regular awareness, education and training
- 3 (=) Tailored dementia-specific support structures
- 4 (=) Policy and legal framework
- 5 (=) Appoint dementia advocates with a specific role
- 6 Pre-diagnosis support for people with dementia and their carers
- 7 Identify and address potential financial issues
- 8 Identified community support for self-employed people



Group 5 (Employers and managers)

- 1 A dementia-inclusive workplace that promotes and supports a culture of care, understanding and awareness of person-centred needs
- 2 Access and signposting to specialist practical support on dementia (internal & external), available for everyone in the workplace
- 3 (=) Strengths-based approach to dementia within the workplace for everyone
- 4 (=) Dementia-specific awareness, education and training for everyone in the workplace
- 5 Funding and financial support for employers supporting people with dementia and carers in the workplace
- 6 A framework and infrastructure such as the Disability Confidence Scheme that supports employers make the workplace
- 7 Awareness of dementia-specific network supports (such as mental health first-aider, dementia support peers) within the workplace for everyone



Group 6 (Policy makers)

- 1 Organisational policy development and guidance with legislative compliance
- 2 Awareness, Education and Training, with resources that provides for employers & employees to enable person with dementia stay in employment
- 3 Guidance for practical support and reasonable adjustments
- 4 (=) Enablement plans instead of risk management, supporting people to have agency around decisions in workplace
- 5 (=) Positive and supportive workplace culture and environment, with an inclusive strengths-based ethos

Group 7 (Academics and researchers)

- 1 Individualised support, personhood and relationship-centred support
- 2 Education, training, awareness and stigma reduction
- 3 Identification, recognition, and support for people with dementia in the workplace
- 4 Rights, policy, legal and organisational frameworks
- 5 Identification, recognition, and support for carers of people with dementia in the workplace
- 6 Facilitate and signpost access to support services
- 7 Role of carers and provision of culturally-appropriate support
- 8 Research, innovation and technology



Thematic analysis

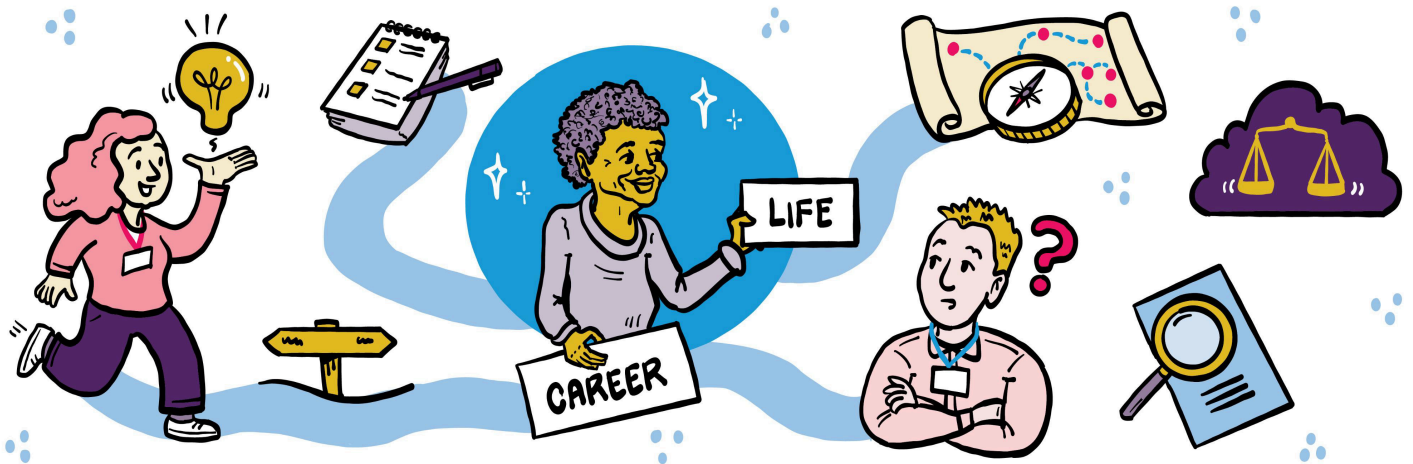
As well as the ideas shortlisted and ranked by each group, we also analysed all the group discussions using a method called reflexive thematic analysis. Three research priorities were identified across stakeholder groups:

(1) Work and wellbeing (exploring the relationship between work, health and wellbeing and how to support continued employment)

(2) Inclusive workplaces (collaboratively developing innovative and inclusive employment practices)

(3) Economic costs and benefits (insights into the financial aspects of working with dementia)

Addressing these areas through future research has the potential to catalyst, support and change expectations and possibilities related to dementia and employment.



If you would like to learn more about Working with Dementia Network Plus, please visit our website:

workingwithdementia.org

You can also email us wwdnetworkplus@uws.ac.uk. We would love to hear from you!



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