



Focus Group - People with Dementia

(18/09/2025)

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 you to take part in a focus group.

What did we do?

Five people in total with a dementia diagnosis joined a two-hour online focus group. At the time of the session, none were in paid employment.



We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified five key priorities to improve workplace experiences for people with dementia and their carers:

- 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).

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



What happens now?

Once all the focus groups are complete, we'll share a detailed summary of the findings with you.

Want to stay updated on the wider Working with Dementia Network?

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Focus Group - People with Dementia

(30/10/2025)

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 you to take part in a focus group.

What did we do?

Eight people in total with a dementia diagnosis joined a two-hour online focus group.



We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified four key priorities to improve workplace experiences for people with dementia and their carers. The group emphasised that all the ideas were important irrespective of ranking:

- 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.

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



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Focus Group - Carers

(02/10/2025)

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 you to take part in a focus group.

What did we do?

Seven people in total with experience caring for someone with a dementia diagnosis joined a two-hour online focus group.

We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified six key priorities to improve workplace experiences for people with dementia and their 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)**

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



What happens now?

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Focus Group - Carers

(23/10/2025)



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 you to take part in a focus group.

What did we do?

Seven people in total with experience of caring for someone with dementia joined a two-hour online focus group.

We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified eight key priorities to improve workplace experiences for people with dementia and their 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

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



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Focus Group - Employers

(06/10/2025)

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 you to take part in a focus group.

What did we do?

Five people in total with experience as employers or managers joined an online focus group.

We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified seven key priorities to improve workplace experiences for people with dementia and their carers:

- 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

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



What happens now?

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Focus Group - Policy Makers

(13/10/2025)

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 you to take part in a focus group.

What did we do?

Five people in total, with experience related to policy development, joined an online focus group.



We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.



What did we find?



The group identified five key priorities to improve workplace experiences for people with dementia and their carers:

- 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

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.

What happens now?

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Focus Group - Academics and Researchers

(20/10/2025)

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 you to take part in a focus group.

What did we do?

Ten people in total working in academia or research roles joined a two-hour online focus group.

We asked:

'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?'

How did we do it?

We used a method called Nominal Group Technique (NGT). This helped us gather and agree on ideas as a group. Everyone shared their ideas and anonymously ranked them. We looked at the results together and had a final discussion.

What did we find?



The group identified eight key priorities to improve workplace experiences for people with dementia and their carers:

- 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

What do we still have to do?

We still need to analyse the discussion that took place between participants, and this will provide depth of detail and contextual information that will offer further insight into the priorities of this group.



What happens now?

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