Share your experiences of peer support

Share your experiences

- Third ‘Share your experiences’ campaign
- Launched on 24th March 2026
- Ran for five weeks
- Campaign utilised:
  - dedicated webpage and survey form
  - social media
  - newsletter
  - direct emails

Aim of the campaign

To gather insight into:

- Types of peer support younger people access
- Benefits they experience
- Barriers that prevent them from taking part

Responses

- **168** people took part
  - **29%** people with young onset dementia
  - **65%** family members or friends

Peer support groups

- **42%** said they currently attend a group
- **11%** said they had attended a group in the past but no longer do so
- **46%** said they had never attended a group

Types of groups attended

- **67%** face-to-face
- **25%** online
- **7%** both face-to-face and online support

Who is the group for:

- **25%** people living with young onset dementia
- **21%** family members and carers
- **27%** both family members and people with dementia
- **19%** dementia group but not specifically designed for younger people

People who currently attend groups

- **72%** have attended for more than one year
- **78%** social or informal groups
- **54%** also offer information and advice
- **22%** activity or creative

Wide range of group activities:
Walks, games, quizzes, informal chats, shared meals and talks from professionals

People who currently attend groups

- **96%** said it helped them connect with others and share experiences
- **87%** said they gained practical advice
- **78%** said it reduced feelings of isolation or loneliness

Finding a peer-to-peer support group changed everything for me. **It gave me connection, understanding, and hope**.

Being surrounded by others who truly ‘get it’ helped me realise that **life is still worth living** and that **I am not alone** in this journey.

People who do not attend

- **46%** had never attended a peer support group
- **44%** said there were no peer support groups in their area; **47%** were unsure

Main reasons for not attending:

- **57%** meeting times did not work for them
- **29%** caring responsibilities made it difficult

People who do not attend

- **71%** said they had fewer opportunities to talk to people who understand their situation
- **67%** said they miss out on practical tips or advice
- **59%** said they felt more isolated
- **74%** would like the opportunity to meet and talk with others

My husband was diagnosed at 48 years old; we had two very young children.

There was no one and nothing available for people like me and our situation.

Previously attended a group

Reasons for no longer attending:

- **32%** said the group closed or changed
- **21%** said they had little or nothing in common with others
- **40%** gave other reasons, including:

'I have primary aged children, and the young onset dementia group is **not within school hours**'

'Found support group **not suitable** as not for young onset dementia'

Previously attended a group

When asked what they missed most:

- **58%** meeting people who understood their situation
- **58%** feeling supported and understood
- **53%** feeling less isolated

- **42%** said they would like to access peer support again in the future; **37%** were unsure

Support for children

- **73%** said they had children
- Only **10%** said their children had access to peer support

‘My kids are 12 and 14 with a dad with young onset dementia. **There is no peer support for them.** The young carers group didn’t help as the other kids weren’t looking after someone who has dementia.’

Key findings

- Peer support: helps people feel understood, connected and less alone
- Benefits: opportunities to share experiences, gain practical advice and build supportive relationships with others
- Significant gaps in provision and lack of knowledge about what is available locally
- Lack of support for children and young people