

Can a peer-led course for people with dementia offer helpful post-diagnostic support?

People with dementia can gain confidence and build social connections by taking part in a co-produced peer-led course. Those who took part in the Good Life with Dementia course, whether as a peer-tutor or as a learner, said they felt more able to face the future living with dementia.

The key is to create a safe space where people are enabled to share experience. This might look different for people in different communities. Involving local people with dementia in the design and delivery of each iteration of the course can help.

Success is underpinned by having peer tutors and peer-learners alongside professional facilitation. The facilitator supports tutors with dementia to take a lead where they can and helps to scaffold a network of ongoing support beyond the life of the course.

Things to be aware of:

- **Whilst the approach has a peer-led ethos, proactive facilitation is necessary** to organise the course and create a safe space where people feel confident to share and support each other.
- **Some people may choose not to self-disclose** but may still get something out of the course.
- **South Asian people who were asked about the model** welcomed the opportunity for support and advice but wanted parallel courses for the carers of people with dementia.
- **There was some concern that the responsibility of being a peer-tutor** could be felt as a burden. The facilitator's role is to ensure tutors are supported to contribute what they can and that this contribution, large or small, is recognised and nurtured, but not burdensome.
- **Dementia can be experienced differently in different communities.** People from South Asian communities were keen to find and build connections across cultural boundaries. An open inclusive approach that does not privileged one type of knowledge over another is essential.

Background

Studies of support for people newly diagnosed with dementia have repeatedly highlighted gaps in provision and noted that services often fail to meet people's needs holistically. In the weeks and months following a diagnosis of dementia, people can face uncertainties, with nagging questions and nowhere to take these. People with dementia also report feeling 'invisible' as their dementia progresses, with professionals directing information and advice primarily towards family carers.

Peer-support was one approach identified in the UK's 2012 Dementia Strategy as promising and in need of more research. The Good Life with Dementia course is a co-produced course developed and run with people with dementia for people with dementia.

The Research

The University of York has been working with previous peer-tutors living with dementia, together with Innovations in Dementia, Meri Yaadain and a host of other stakeholders, to learn more about the Good Life model. They conducted a realist evaluation between January 2023 and March 2024 to understand how and in what contexts this approach could influence outcomes for people living with dementia and how transferable it might be to other settings: see <https://bit.ly/49Wt2YB> or scan

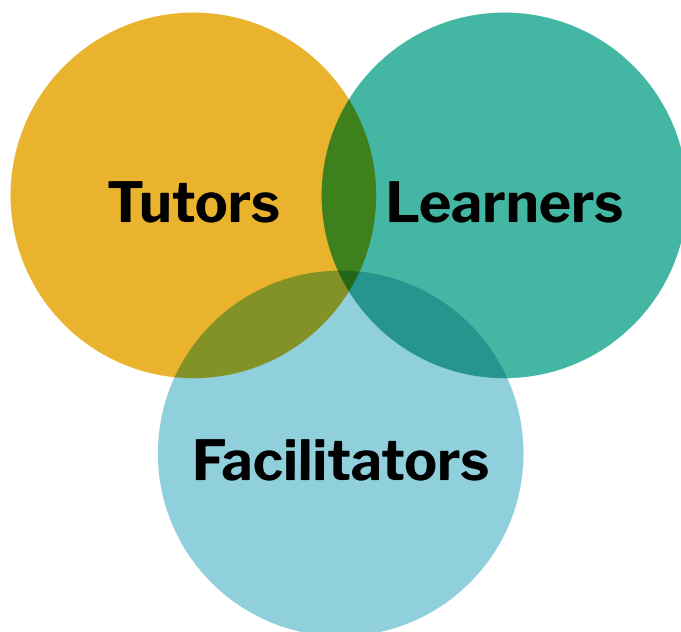


The Good Life model

Most courses about dementia were designed by professionals and are directed, at least in part, towards carers. The starting point for the Good Life model was a question for people living with dementia themselves: 'What messages would you want to give someone recently diagnosed with dementia, based on your own experience?' Their answers formed the basis of the first Good Life course.

The model typically consists of

- **A 6- or 7-week commissioned course facilitated by a professional**, who supports peer-tutors living with dementia to take a lead where they can.
- **Tutors are ideally learners from a previous course.** Learners are people newly diagnosed with dementia signposted by local memory and voluntary services.
- **Course content is agreed with people living with dementia at pre-course co-design sessions.** A core element of the format is open discussion about topics of interest, including living with dementia itself, but the facilitator also arranges for experts and local services to speak about specific subjects and to answer questions.
- **The facilitator encourages at least one local professional to observe the sessions** to learn the approach and help support the developing social group beyond the life of the course.
- **Family carers are not encouraged to attend** but to socialise in an adjacent room. They and the person with dementia are sent a letter summarising what was covered after every session.



Research findings

People with dementia on the Good Life course reported the following outcomes:

- **Feeling seen, valued and valuable.**
- **Gaining confidence and social connections.**
- **Feeling more able to face the challenges dementia presents in future.**

The mechanisms likely to produce these outcomes are:

- **Sharing experience with other people with dementia in a safe space**
- **Personalised learning and responding**
- **Taking on meaningful roles**

The context in which these mechanisms took place was:

- **A safe space characterised by shared experience, equality, positive expectations and a friendly, trusting atmosphere.**
- **This could look different for different communities but would be welcomed by all.**

Research methods:

The University of York worked with partners, including people living with dementia, to conduct a realist evaluation of the Good Life model between January 2023 and March 2024. We observed two Good Life courses, heard from 22 participants with dementia and conducted focus groups with 67 additional participants about the transferability of this model in diverse communities. The research was funded by the NIHR Three School Dementia Research Programme and had ethical approval from the HRA.

Go to our webpage for more information <https://bit.ly/49Wt2YB> or contact kate.gridley@york.ac.uk