

## Background

Empowered Conversations is a 6-week, group communication course provided by Age UK Salford to family caregivers of people living with dementia.

Based on the Communication Empowerment framework<sup>1</sup>, the course aims to improve communication by supporting caregivers to be aware of the psychological and relational aspects of their communication and identifying alternative ways to approach interactions.

Earlier research has demonstrated that the course can improve communication and reduce stress for caregivers<sup>2</sup>.

A 2-year randomised controlled trial (RCT) of Empowered Conversations was conducted (2021-2023) to evaluate the feasibility of running a multicentre trial of the course<sup>3</sup>.

75 family caregivers from Greater Manchester were recruited as participants for the RCT.

A nested qualitative study was included in the trial design.

## Aims

To explore:

1. Caregivers' experiences of the online Empowered Conversations course
2. What changes they had seen in their everyday life after completing the course.

## Methods

Semi-structured interviews were completed with fifteen caregivers who had completed an Empowered Conversations course as part of the RCT.

Applied thematic analysis was used to develop 4 themes and 9 sub-themes (shown in **bold type**) that captured their experiences.



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# Empowered Conversations: Rethinking communication for carers of people living with dementia

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## Delivering Empowered Conversations

Overall, the **course content and format** of Empowered Conversations were acceptable to participants.

Facilitators were seen as knowledgeable, friendly, and approachable.

*We were all made very welcome and although I think there might have been one or two of us that were a little bit camera shy, if you like, but they made you feel comfortable and weaned you in.*

The **online** format was ok for all participants, but most preferred the idea of in-person groups.

All participants could see advantages to the online format (easier for planning and practicalities).

In-person groups were associated with better communication and connections.

People felt that the course is best for people who are **early but not too early** in their caring journey; they need time for the diagnosis to 'soak in'.

## A community to share together

Participants valued being part of a group. They had the **freedom to be honest and vulnerable** and could say things that they might not want to share with family or friends.

*It became a safety net. For those six weeks, it became like a community of like-minded people that could share with two people that could provide us with help and support.*

They felt **understood because of what they shared** with other people in the group. The other caregivers had been through similar experiences and could understand theirs.

However, if circumstances were *too* different (e.g., ages, caring responsibilities) some people felt less connected with others.

**Other people's stories resonated with and educated** participants. Hearing from the experience of others helped participants make sense of past or current experiences. They could also learn from situations that other people had faced.

However, hearing about what might happen in the future was sometimes considered to be "a double-edged sword".

## You've got nothing to lose and everything to gain

Participants had different motivations for taking part in the research, but there was a sense that the course was not too much of a burden for people to 'have a go'.

Some people felt lost and alone after being told the diagnosis and were keen to access any information or support that was on offer.

Those who had more post-diagnostic support were able to build on existing knowledge and share new learning from Empowered Conversations with peers at other groups.

*There's a really strong supportive element to it, there's a really strong content element that you can refer to...And for six weeks, you've got nothing to lose, you've got everything to gain.*

The mix of information and support meant that people were able to take away what they needed. Even if it was not needed at the time, people identified they could go back to the course resources when things changed.

## Being given a new way to see the world

Learning more about dementia and thinking about how it might affect someone's communication helped caregivers **understand the person through the lens of dementia**.

Empowered Conversations gave people the knowledge and skills **to recognise control in communication**.

They realised what they could control (e.g., changing their non-verbal responses) and learned how to give the other person more control in the conversation (e.g., giving more time for them to respond).

People also learned to **recalibrate their expectations**, learning to adjust to how the person responds and acts now, instead of comparing this with how they did things before having dementia.

*When I thought that perhaps she didn't understand a lot of what was going on around her, actually she did but she wasn't able to express it. By doing this course it opens up a whole new world for everybody, and life doesn't seem as hopeless as you think it is.*

## References

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