

# Good Life with Dementia Research Project

## Plain English Summary

**Why we are doing this:** People often feel unsupported by services after being diagnosed with dementia. Many worry about the future but are unsure where to turn for help.

***Good Life with Dementia (Good life)*** is a community-based course co-produced by people living with dementia to help other people diagnosed with dementia by sharing experiences and resources. Our first Three Schools funded study found Good Life could help people face the challenges dementia presents. We also explored how it might help people from different cultures, by talking to people affected by dementia in South Asian communities.

**Aims:** We want to find the best way to trial the Good Life course. A first step is to see if we can run the course consistently in different places and with different communities. We will also develop and then test a plan to evaluate the outcomes of the course.

**Research plan:** Trials are studies that divide participants into groups so that some get the new treatment (in this case the Good Life course) and some get usual care. Both groups are asked about their wellbeing at the beginning, middle and end of the trial to see if the new approach works better or worse than usual care. To plan a Good Life trial, we need to know:

- Will people join a study if they might not get to go on the course?
- Can we consistently collect information from participants at three time points?
- Are we asking the right questions to understand how the course affects people?
- Can we meet the different needs of people from White British and South Asian communities?

To answer these questions, our study has 3 phases:

1. Collaboratively develop a manual and training plan for Good Life facilitators. This will help make sure the course is delivered in the same way everywhere.
2. At the same time, work with partners to set up our small trial (called a feasibility trial) to find out what we need to know for the main trial.
3. We will then run the course in three community settings, including one specifically for South Asian people, to answer our questions about how a full trial could work.

**Working with diverse people and people with lived experience:** Our applicant team includes two people who are living with dementia and have personal experience of the Good Life course. We also work closely with South Asian community groups affected by dementia and will set up an advisory network of people with lived experience and practitioners with a dedicated South Asian sub-group, to help us to design culturally appropriate research documents and processes.

**Using the research:** This research will provide knowledge needed to plan a full trial of the Good Life course as well as resources to help other groups to run the course. We will work with our extensive networks of stakeholders and members of our strategic advisory group to ensure the learning is used to improve dementia support for all.