

A Good Life with Dementia



Kate Gridley kate.gridley@york.ac.uk
Rachel Mann rachel.mann@york.ac.uk

Realist evaluation of a post-diagnostic peer-led course, run by and for people with dementia

<https://www.york.ac.uk/business-society/research/spsw/good-life-with-dementia-course/>

Realist evaluation of a post-diagnostic peer-led dementia course

A collaboration:

- University of York
- Previous course tutors with dementia
- Innovations in Dementia CiC
- Meri Yaadain CiC
- Hull York Medical School
- Tees, Esk and Wear Valleys NHS FT
- Primary Care



FUNDED BY

NIHR | National Institute for Health and Care Research

The Good Life course:

By people with dementia, for people with dementia

A GOOD LIFE WITH DEMENTIA

A post diagnostic course for people living
with dementia

People with dementia as
course designers

People with dementia as
course tutors



Realist evaluation aims: To test and refine underlying theories of change

How the Good Life course ‘works’:

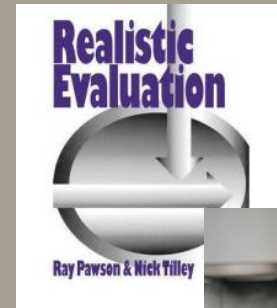
- What are the key mechanisms or ingredients?

In what contexts?

- For whom? In what situations might it *not* work?

What might be the outcomes?

- What do we mean by ‘works’?



Theory of change – like baking a cake:

Ingredients
(mechanisms)



Who is the cake
for?



What else is
going on?



Who is baking
it?



How hot is the
oven?



Where/what's the
kitchen like?



Importance of context

- ▶ You can use the same ingredients...
- ▶ But if someone else is baking (or decorating) it can go quite differently!



← (my attempt)

Methods and progress

Pre-study: Stakeholder workshops to agree initial theory of change

Study: (15 month project: 1st Jan 2023 to 31st March 2024)

1. Review the published literature on peer-support models (rapid review of reviews)
2. Observe Good Life with Dementia peer-led course sessions (two courses)
3. Qualitative interviews with learners and tutors
4. Focus groups with people from South Asian communities



Post-diagnostic peer-led training for people
with a new physical or mental health
condition: a rapid realist overview of
reviews

- Aim to identify the existing literature and substantive theory underpinning the outcomes of peer-led support
- For people with a diagnosis of a new physical or mental health condition

What's a realist review?: The CMO Context-Mechanism-Outcome configuration will be used to reflect on and extract data from all included reviews involving

- Who—the people involved, the health condition(s) they are experiencing, and their sociodemographic characteristics;
- What—the focus and type of support offered, whether education, emotional or practical, and who facilitates it;
- How—whether meetings are in person or online, occur individually or in groups, and the support offered to peer supporters;
- Where—the location of its provision, for example, healthcare or community settings;
- When—the duration of the intervention.

Our experts by experience and stakeholders preliminary Theory of Change

- Context
- Tutors have been previous learners on a living well with dementia course
- A close working team of facilitators and peer tutors that co-create a community-sensitive Good Life course
- Collaborative and shared action planning for developing and delivering a Good Life course in a local community
- Mechanisms
 - Role modelling 'living well with dementia'
 - Positive expectations
 - Being open about own feelings and experiences
 - Confronting dementia
- Outcomes
 - Knowledge about condition, hope, empowerment, confidence, social connectedness, access to community resources

Watson, E. (2019). The mechanisms underpinning peer support: A literature review. *Journal of Mental Health*, 28(6), 677–688.
<https://doi.org/10.1080/09638237.2017.1417559>

- **Lived experience**
- **Love labour**
- **The liminal position of the peer worker**
- **Strengths-focussed social and practical support**
- **The helper role**

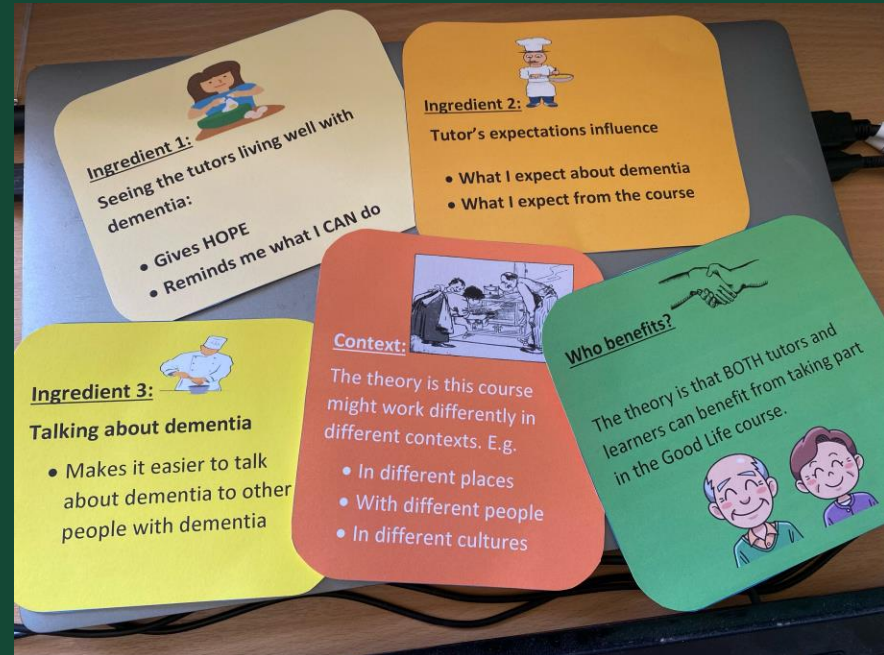
What are our objectives?

- To identify context, mechanism and outcome theories in published reviews which could help explain understand how and in what circumstances why any potentially relevant peer-led post-diagnostic support and/or training works (or does not work)
- To synthesise the findings from objective 1, and to identify and understand the potential mechanism/s by which a peer-led training and/ or other peer-support interventions may lead to the outcomes
- To use the findings from objective 2 to help refine the preliminary programme theory (theory of change) to be tested in the empirical work to evaluate the Good Life with Dementia Approach

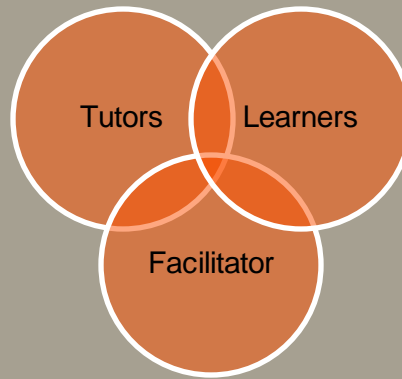
Interviews and observations

Course 1	Participants	Others
Observed 5/7 sessions	12 learners, 2 tutors	Facilitator, speakers and supporters

Interview	Gender	Ethnicity
Int 1	Male	White British
Int 2	Female	White British
Int 3	Female	White British
Int 4	Male	White British
Int 5	Male	White British
Int 6	Female	White British
Int 7	Female	White British



Early findings?



Importance of facilitation

An opportunity to talk openly:

- Relaxed atmosphere highly valued by interviewees
- Some said they had few other opportunities to talk about their diagnosis socially/in this relaxed way (only in clinical settings or with spouse)
- Lots of laughter!

Shared lived experience:

- Shared experience is important (*it's not just me*)
- This was in the literature but not explicitly in stakeholder generated theory of change

Ongoing access to community support:

- Source of information
- The group itself is social network which will continue after the course...



The Good Life course:

By people with dementia, for people with dementia

A GOOD LIFE WITH DEMENTIA

A post diagnostic course for people living
with dementia

People with dementia as
course designers

People with dementia as
course tutors



Disclaimer: This presentation summaries independent work funded by the National Institute for Health and Care Research Three Schools' Dementia Research Programme. The views expressed in this presentation are those of the author(s) and not necessarily those of the NIHR SSCR, the NIHR or the Department of Health and Social Care.



Questions? Comments?



Key contacts:

Kate Gridley, Co-PI, kate.gridley@york.ac.uk

Rachel Mann, Research Associate, rachel.mann@york.ac.uk

Mark Wilberforce, Co-PI, mark.wilberforce@york.ac.uk

<https://www.york.ac.uk/business-society/research/spsw/good-life-with-dementia-course/>