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A Good Life with Dementia



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

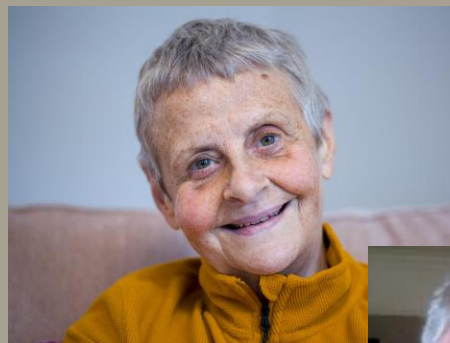
Realist evaluation of a post-diagnostic peer-led course, run by and for people with dementia

<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



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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’:

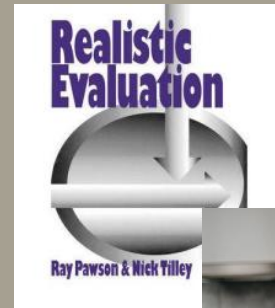
- What are the key mechanisms or ingredients?

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

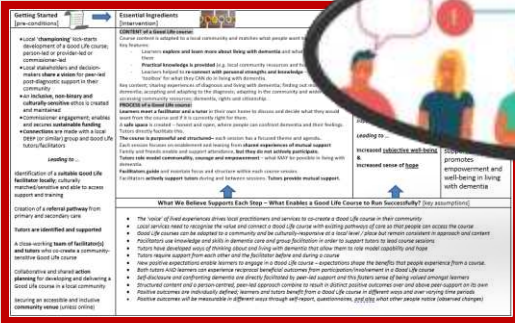
Pre-study: Stakeholder workshops to agree initial theory of change

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



Stakeholders co-created some candidate theories...



Context:

- Local champions
- Engaged commissioners
- Shared vision

Mechanisms:

- Positive expectations
- Seeing others living with dementia
- Self-disclosure and confronting dementia

Outcomes:

- Knowledge about living with dementia
- Access to support and resources
- Confidence
- Empowerment
- Community connection
- Wellbeing
- Hope

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**

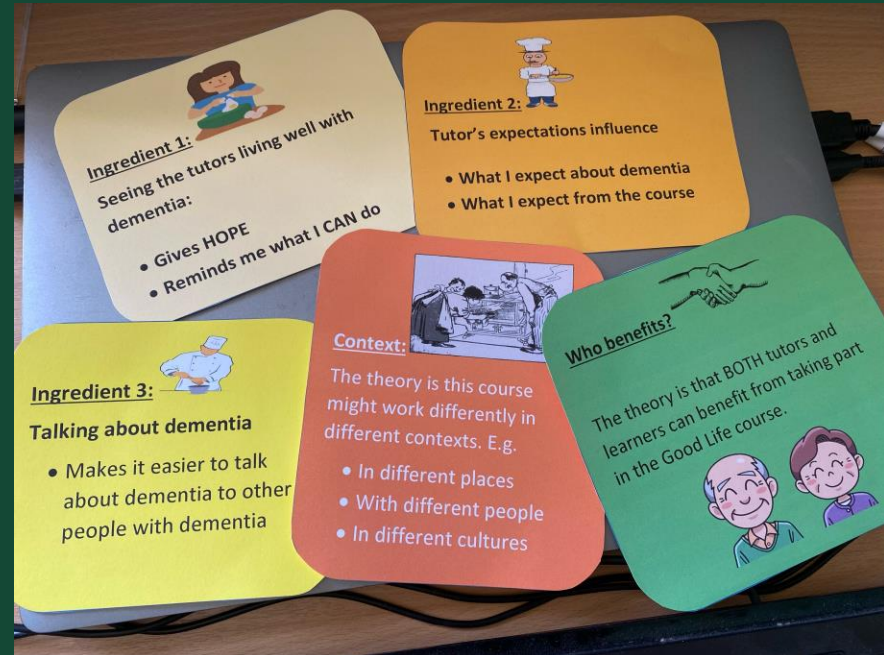
What are our objectives?

- 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

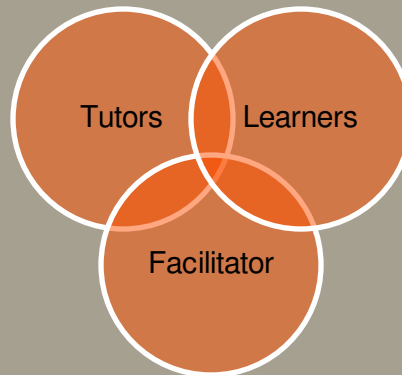
Interviews and observations

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...



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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/>