

**Recovery and living well with dementia:
Evaluations from a co-designed course in a Recovery
College for people living with dementia and their care
givers**

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The people we serve

Lincs population of 718,800

Large rural county
of 2646 sq miles

56 Trust locations



Challenges

- Higher than average proportion of population in Lincolnshire are older people
- Increasing numbers of people with dementia
- Health service with limited resources that end up only responding to crises

Recovery Colleges

- Developed in the last decade
- Aim to support people to become experts in their own self-care
- Aim to increase understanding and awareness for families, friends and carers in order that they can support people in their recovery journey
- An alternative way of providing some interventions

Defining features of a Recovery College

- Co-production of courses between people with personal and professional experience of mental health problems
- Educational approach rather than therapeutic
- Encourages people to do their own research and find their own solutions (self management)
- Its open to everyone
- Values peer support

“...but people with dementia don't recover...”

- The term ‘recovery’ is synonymous with being free from illness
- However if ‘recovery’ is defined as the process through which people find ways of living meaningful lives with or without ongoing symptoms then it can be applied to people with dementia

Key components of recovery

- Connectedness
- Hope and optimism
- Positive sense of identity
- Quality and meaning in life
- Empowerment

How can self management help someone living with dementia?

- Self-management of dementia requires the individual to understand the illness and use strategies to cope with their symptoms, so that independence can be retained for as long as possible.
- It draws on the potential that a person has to retain skills and abilities and, as a consequence, maintain activity and relationships with others, including with their communities.
- There is a growing body of evidence to demonstrate that individuals can be supported to maintain their skills for longer and build resilience
- Self management is also vital for the caregiver

Peer Support

- Two way process so can be mutually beneficial
- It is about understanding another's situation with empathy through a shared experience
- Helps people not feel alone or stigmatised
- People often share strategies or information
- Supporting someone else can increase feelings of wellbeing

Co-design of the LWWD course

- Exploring what people want and need
- It requires professionals to respect participants and the knowledge that they bring to the process
- In Lincolnshire we have also involved nursing students and other stakeholders in the co-design and delivery
- However it is timely

Living well with dementia

2 hour sessions once per week for 8 weeks

Topics covered

- Information about dementia
- Maintenance of an active lifestyle
- Staying well
- Practical ways to manage memory difficulties
- Psychological wellbeing
- Maintaining relationships and social networks
- Planning for the future
- Coping skills
- Finances
- Accessing local resources

What did we Evaluate?

Small study of 2 cohorts of 12 people

- DEMQOL and DEMQOL Proxy Pre and Post
- Zarit Carer Burden Pre and Post course
- Focus groups

DEMQOLS

- Some small improvements in aspects of mood and feeling positive (no deteriorations noted)
- No improvements or deteriorations noted in memory
- Some small improvements in level of worry around activities in daily living (no deteriorations noted)
- Overall quality of life maintained for majority as good (no deteriorations)

DEMQOL proxy

- Some small improvements in aspects of mood and feeling positive (no deteriorations noted)
- Most participants maintained but 2 noted small deterioration in memory
- Some small improvements in level of worry around activities in daily living (no deteriorations noted)
- Overall quality of life maintained for majority as good or fair (no deteriorations)

Zarit Carer Burden

Most significant improvements were

- Significant impact on social life
- Felt more confident having friends over
- Felt able to manage longer
- Felt more in control
- Can continue caring longer
- Had more time to myself
- Feel I have enough money to take care of relative and other commitments

Zarit Carer Burden

Small improvements in

- Felt less stressed about trying to meet other responsibilities
- Felt health may have improved
- Feeling less uncertain
- Feeling I should be doing more
- Felt they are doing a good job

What did people say?

- Didn't feel like a medical group – relaxed and informal
- Great to be identified as a student!
- Learnt hearing from others and the professionals
- Helped me understand what was going on and that helped me respond in appropriate way
- No one had ever really explained what dementia was to me
- Reduced some of the fear
- Looked forward to coming and getting things off my chest

- Group/peer support was great and could share things and experiences which helped reduce isolation and feeling like you are the only one in this situation
- Shared tips and ideas of dealing with situations
- Everyone was involved in the sessions
- Talked about some things I may have found difficult to raise out of the group eg relationships
- Good to learn together (person with dementia and care giver)
- I think we have a better understanding of each other
- I have met some good friends and we have plans to stay in touch

The benefits of hosting in a Recovery College

- The courses are open to anyone
- People enrol as students
- No psychological/memory testing to attend – just need to be able to participate in a group setting
- People have had opportunities to attend other courses that will support them and the people they may be supporting to live well

In summary

- Early evidence suggests that introducing courses for self-management for people living with dementia and their care givers in a Recovery College has the potential for far reaching implications for services in Lincolnshire and wider
- Supporting people to live well and learn both proactive and reactive coping strategies which help them manage the challenges they may be facing as a group can be beneficial
- Future plan is to develop a larger research project

Many Thanks for listening

Any Questions?

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