

# Cognitive rehabilitation for people living with dementia: a practical framework for enablement

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## Rehabilitation and people with dementia

- Tackling barriers to participation and inclusion for people living with mild to moderate dementia in the community
- Enabling people to function as well as possible – the role of rehabilitation
- People living with dementia are advocating for their right to rehabilitation
- Rehabilitation approaches for people with early-stage dementia – cognitive rehabilitation (CR)

## Cognitive rehabilitation (CR) for people with early-stage dementia

- With the right support people with mild to moderate dementia can adjust, learn strategies, and learn new skills
- The starting point is what people with dementia would like to change, improve or manage better
- Potential targets include everyday functioning, activities of daily living, self-care, language and communication, and social interaction
- CR is a personalised intervention, and is carried out in the person's usual setting so that it is directly related to daily life

## What do CR therapists do?

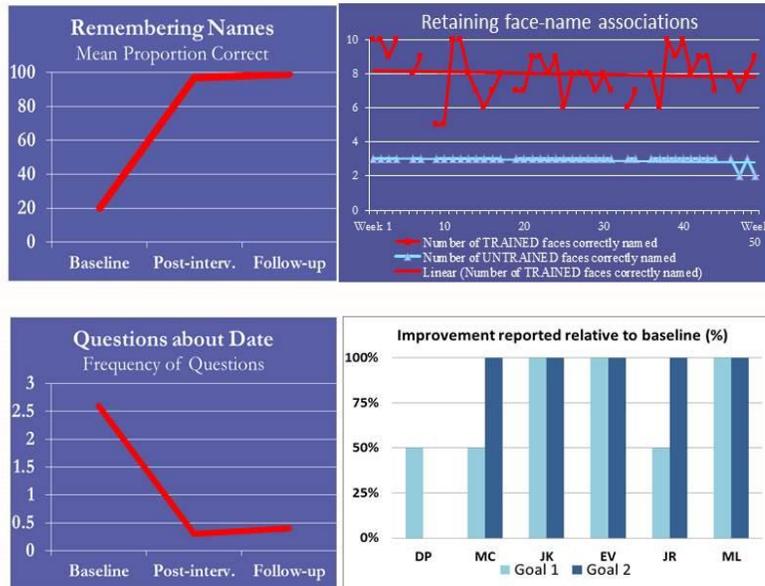
### Use a collaborative, problem-solving approach to find out:

- What the person is currently doing and could potentially do, and how the person's environment supports or hinders functioning
- What the person wants to achieve (goal) and what s/he needs to be able to do in order to attain this goal
- Where there is a mismatch between what the person can do and what the goal requires, and where and why things go wrong

### Use a collaborative, solution-focused approach to:

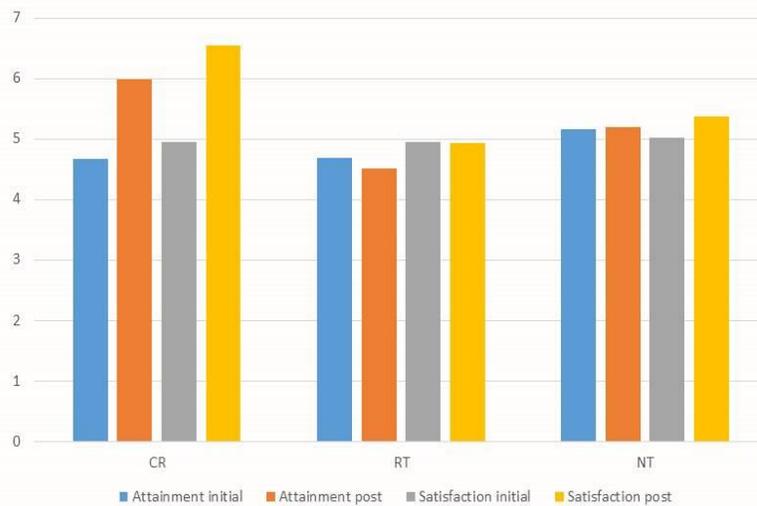
- Plan how to address the goal using evidence-based rehabilitative methods - these could involve new learning, relearning, use of compensatory strategies or assistive technology
- Include other behavioural approaches where needed, such as anxiety management or behavioural activation
- Support the person in carrying out the plan, and monitor progress
- Enable family members or other carers to support the process

## Feasibility studies of CR



Clare et al, 1999, 2000, 2001, 2008

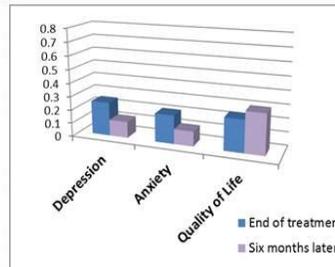
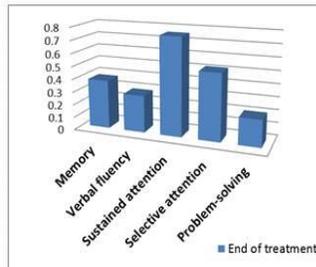
## Pilot RCT: participant goal attainment



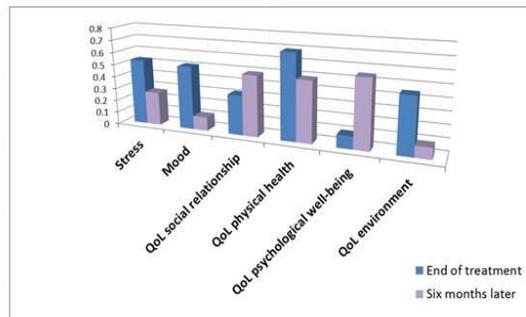
N=69 randomised; Clare et al., 2010

## Initial RCT: other positive findings

Participants with dementia  
*CR > control*



Carers  
*CR > control*



Clare et al., 2010

## The GREAT trial: Goal-oriented cognitive Rehabilitation

Aim: to definitively establish whether CR is beneficial for people with early-stage AD, VaD or mixed dementia

Participants: We included 475 people with dementia, each with a family member as study partner. Participants had a diagnosis of Alzheimer's, vascular or mixed dementia and an MMSE score of 18 or above

Recruitment: 1<sup>st</sup> April 2013 to 31<sup>st</sup> March 2016



## What happened in the GREAT trial?

- All participants identified goals and rated how they were currently doing (goal attainment). Study partners made an independent rating
- Half were randomly selected to receive CR while the rest continued with treatment as usual (TAU)
- CR participants had 10 weekly home visits from a CR therapist over 3 months
- All participants and study partners rated goal attainment again after 3 months
- CR participants had 4 more therapist visits over the next 6 months
- All participants and study partners rated goal attainment again 9 months after starting in the trial
- Other ratings - quality of life, mood, cognition, service use

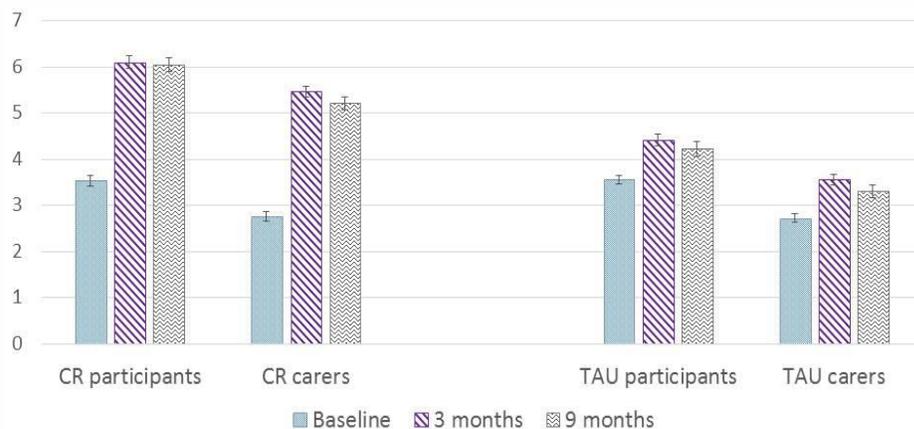
## What kinds of goals did GREAT trial participants choose?

- Engaging in activities and personal projects
- Trying challenging activities
- Using appliances, devices and gadgets
- Managing everyday tasks and situations
- Managing shopping, cooking and baking
- Remembering names and other details
- Retaining information and events
- Knowing what's happening
- Finding belongings
- Finding the way to places
- Engaging in conversation
- Keeping in contact with family and friends
- Managing emotions
- Caring for oneself

## Examples of goals that were addressed in GREAT

- John wanted to overcome the fear of using household appliances, mobile phones and other technology that was undermining his independence
- Doris wanted to regain the confidence to collect her pension from the post office, and to stay safe by remembering to lock her door at night
- Shahid wanted to feel better able to engage in conversation, and resume his activities and interests
- Gareth wanted to stay independent and cook his own meals without burning the food, and to remember the names of his grandchildren

## Did CR participants attain their goals?



No significant changes in other measures

## Participant and study partner views

Interviews by an independent researcher revealed that:

- The therapist enabled participants and study partners to develop and personalise rehabilitative strategies
- The relationship with the therapist was important
- The therapist also provided information, education and support
- There were improvements in participants' daily activities, and in well-being and quality of life for both
- The intervention empowered them and helped with the psychological adjustment to living with dementia
- They felt more confident, less anxious, and better able to cope

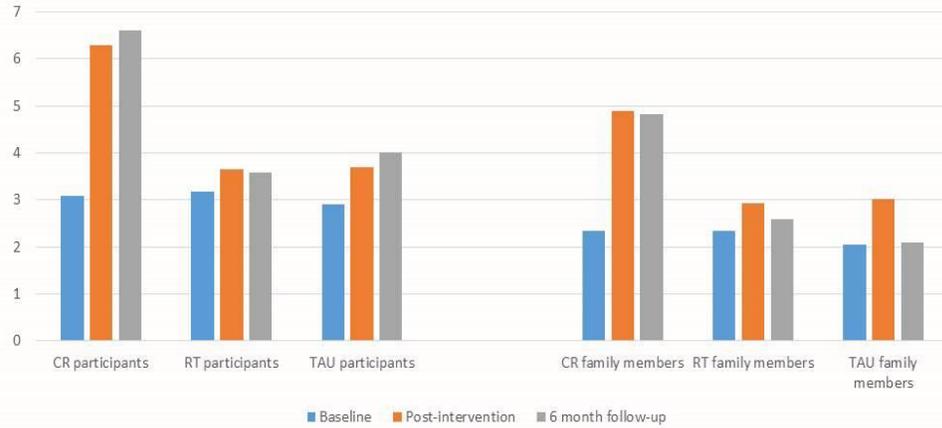
“She explored areas, you know, that I hadn’t thought about, and...I found it a great help.” [Person with dementia]

“(...) sometimes just reaching his goal, being able to do it after a few days. (...) Just little things like that, they help I think.” [Family member]

“The therapist made you think about things that you thought you perhaps knew, but think about them in a different way ... and approach them in a different way.” [Family member]



## CR for people with Parkinson's disease dementia and Lewy body dementia: CORD-PD



*Other benefits were also observed e.g. more positive quality of life ratings by both participants and family members*

N = 29 randomised; Hindle, Watermeyer et al., 2018

## Other emerging evidence

Study	Intervention	N	Duration	Intervention cf. control
Amieva et al 2015 (ETNA-3) France	Individual goal-oriented CR + carer telephone support	CR n=157 Control (usual care) n=154	Weekly for 3 m + 6-weekly for 21 m	↓ functional decline at 24 m (DAD); 6 m delay in institutionalisation. No other differences.
Kim 2015 South Korea	Individual goal-oriented CR + group Cognitive training (CT)	CR + CT n=22 Active control n=21	Weekly for 8 weeks	↑ goal performance, QoL and orientation (MMSE questions) at 8 weeks.
Thivierge et al 2013 Canada	Structured training of problematic IADLs	Immediate training n=10 Wait-list control n=10	Twice-weekly for 4 weeks	↑ performance of trained IADLs under observational assessment conditions at 8 weeks, maintained at 3 m. No differences on secondary outcomes.
Voigt-Radloff et al 2017 (REDALIDEM) Germany	Structured training of tasks and activities using errorless or trial-and-error methods	Errorless training n=81 Trial-and-error training n=80	9 one-hour sessions over 8 weeks	↑ performance of trained IADLs with both training methods under observational assessment conditions at 16 weeks, maintained at 6 m. No differences on secondary outcomes.

## What have we learned so far?

- It is possible to improve and/or maintain specific everyday skills in the early stages of dementia
- Personalised, goal-oriented cognitive rehabilitation can help people with early-stage Alzheimer's, vascular or mixed dementia to improve their everyday functioning in relation to individual goals targeted in the therapy
- CR could form a useful component of post-diagnostic care pathways and community reablement or home care packages
- Because it is based around personal goals, cognitive rehabilitation could be adapted for different settings or cultures

## CR is recommended in the UK

NICE Guideline - Dementia: assessment, management and support for people living with dementia and their carers (NG97)

- NICE guideline Published: 20 June 2018
- [nice.org.uk/guidance/ng97](http://nice.org.uk/guidance/ng97)
- *1.4 Interventions to promote cognition, independence and wellbeing*
- *1.4.4 Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.*

The Memory Services National Accreditation Programme recommends that services offer CR to people with early-stage dementia

## Implementing GREAT CR : GREAT into Practice (GREAT-iP)

- Introducing GREAT CR into practice in 15 partner organisations providing health or social care
- Co-producing resources with people with dementia, carers and practitioners
- Working with each partner organisation to create and implement a tailored and sustainable implementation plan
- Encouraging adoption through staff training followed up with ongoing supervision and support
- Creating a community of practice



## Reflections

- Focusing on enablement is central to supporting people to live as well as possible with dementia
- Acknowledging the relevance of rehabilitation offers a tremendous opportunity to create a coherent approach to positive support for people with dementia, of any age, subtype, or severity, and their families
- A rehabilitation model offers a guiding framework for services and for health and social care practitioners and a practical means of providing person-centred, evidence-based interventions to maintain or enhance functioning, engagement, participation and inclusion

## Further information

REACH: Centre for Research in  
Ageing and Cognitive Health,  
University of Exeter

Further information about  
GREAT CR and GREAT-iP:

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The screenshot shows the University of Exeter website. At the top, there is a navigation bar with links for Home, Contact us, Staff, Students, By Exeter, Exeter (Students), Site map, and RSS. Below this is a search bar. The main navigation menu includes Study, Research, Business and community, Working here, Alumni and supporters, Our departments, Visiting us, and About us. A dropdown menu for 'Research in Ageing and Cognitive Health (REACH)' is open, listing links for Who we are, Projects, GREAT Trial, Study protocol, Cognitive Rehabilitation, Participant Recruitment, Meet the team, News, Request further information, Contact us, IDEAL, Publications and resources, Research partners, REACH Network, News, Events, Postgraduate study, Access to data, Get involved, and Contact us. The main content area features a banner for 'Living Well with Memory Difficulties (GREAT Trial)' with a photo of three women. Below the banner is a 'Welcome to GREAT' section with a quote: '\*\*\*You can download articles about cognitive rehabilitation for people with dementia and request to receive information about the guides to cognitive rehabilitation if they become available in the future. You can also download a Guide to Psychological Interventions in Early Stages of Dementia from the British Psychological Society website\*\*\*'. The text below the quote describes the GREAT trial as a large multi-centre trial led by Professor Linda Clare, who developed the cognitive rehabilitation approach for people with memory difficulties and led the pilot study. The trial is co-ordinated from the University of Exeter and is taking place in eight areas in England and Wales. The trial will provide definitive evidence about whether goal-oriented cognitive rehabilitation is a clinically-effective and cost-effective intervention for people with early-stage dementia and their family, friends and/or carers.

Thank you!