

# **Dementia Reconsidered .... with particular reference to the role of Cognitive Rehabilitation**

DEM-REHAB Conference  
26 October 2020

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Dementia Pal Ltd

# Some History .....



# A 38 year journey with dementia

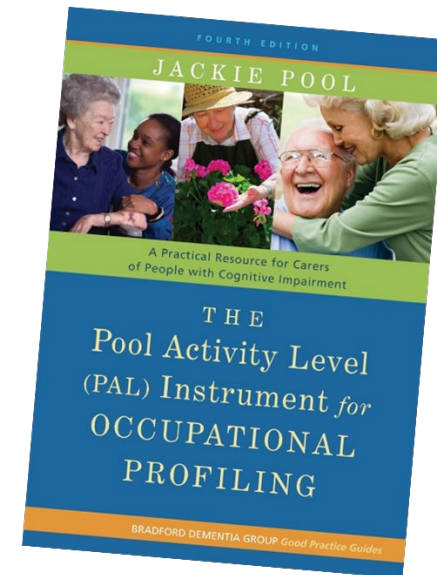
The Dialectics of Dementia with Particular Reference to Alzheimer's Disease. Tom Kitwood. Ageing and Society (1990) 10 (2) p177



Dementia Care Mapping

The PAL Instrument (1999; 2002; 2008; 2012)

Personal experience



# The PAL Instrument<sup>®</sup>

identifies the level of cognitive and functional ability of the individual  
at 4 possible levels of ability

**PLANNED**


**EXPLORATORY**



**SENSORY**

**REFLEX**

To complete the **PAL Instrument**® **Checklist**.  
 You choose the statement that most closely describes the way the person  
 carries out 9 everyday activities



**Pool Activity Level (PAL) Checklist**®

(ref: Pool, J. (2012) The Pool Activity Level (PAL) Instrument for Occupational Profiling. Jessica Kinglsey publishers, London)

**Completing the Checklist**

Thinking of the last 2 weeks, tick the statement that represents the person's ability in each section.

If in doubt about which statement to select, choose the level of ability that represents their average performance over the last 2 weeks.

**You must select one statement for each section.**

**Selections are totalled at the bottom of each column.**

**Key**

P = Planned level of ability

E = Exploratory level of ability

S = Sensory level of ability

R = Reflex level of ability

1. Bathing/Washing	P	E	S	R
Can bathe/wash independently, sometimes with a little help to start.	●			
Needs soap put on flannel and one step at a time directions to wash.		●		
Mainly relies on others but will wipe own face and hands if encouraged.			●	
Totally dependent and needs full assistance to wash or bathe.				●
2. Getting dressed	P	E	S	R
Plans what to wear, selects own clothing from the cupboards; dresses in correct order.	●			
Needs help to plan what to wear but recognises items and how to wear them; needs help with order of dressing.		●		
Needs help to plan and with order of dressing, but can carry out small activities if someone directs each step.			●	

The appropriate **PAL Profile** © can be selected to support the person who is living with dementia and their family and other carers.

Each PAL Profile gives guidance on:

- Likely abilities and limitations
- The care giver role
- Positioning of objects for optimum engagement
- Use of verbal and non-verbal language
- The focus of the activity



The **PAL Instrument**® is a reliable and valid tool that is used around the world in Hospitals, Care Homes and other care settings.



**It is currently being translated into Danish!!**

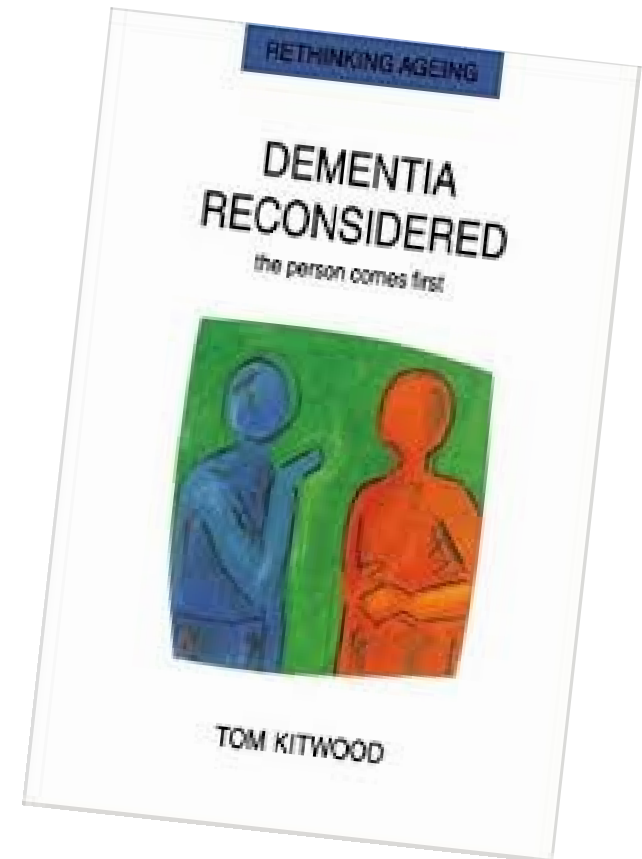


# The concept of Rementia

## Evidence for a more positive view:

- Person centred approaches stabilised cognitive decline and high levels of well being (Bell and McGregor, 1995)
- Rementing - measurable recovery of lost powers and slower cognitive decline (Sixsmith, 1993)
- The potential for personhood for people with very severe dementia (Perrin, 1997)
- Clear evidence that care practice can have neurological consequences and that psychosocial environment affects neuronal growth (Karlsson et al. 1988; Brane et al. 1989)

(pages 61-64)



# What is dementia?

The group name for the symptoms caused by progressive neurological conditions

# What is rementia?

The reduction of the symptoms leading to an improvement in functional ability

*“The older view was that there can only be a one-way journey, from left to right. Now, however, as a richer body of evidence becomes available ... that view is no longer tenable. Some people undergo a degree of ‘rementing’”*

Tom Kitwood (1997) Dementia reconsidered: The Person Comes First

# How can we support dementia?

- ✓ Nutrition
- ✓ Emotion
- ✓ Function



# Function

Impaired Cognition – memory, perception, orientation, word finding, executive functions



Disability

Unless .....

**... we build on the opportunity to deliver rehabilitation and therapeutic environments**

**NICE Guideline 97 Dementia: assessment, management and support for people living with dementia and their carers.** Published 20 June 2018 and recommends:

1. Offer a range of activities to promote well-being that are tailored to the person's preferences
2. Offer group Cognitive Stimulation Therapy to people living with mild to moderate dementia
3. Consider group Reminiscence Therapy
4. Consider Cognitive Rehabilitation or Occupational Therapy to support functional ability.

# Addressing disability in dementia (adapted from WHO, 2001)

Not making a cup of tea

Impairment

Activity limitation

Participation restriction

Cognitive rehabilitation to minimise impairments



Decreased attention

Unable to sequence the steps involved

Unable to recall who wants what

Unable to make a cup of tea

successfully.

No longer makes tea

No longer invites people to the house

Increased dependence upon carer

Excess Disability

(environmental factors)

Cluttered/tidy kitchen

Too supportive carer 'easier for me to do it'

Low self esteem, fear of failure

Cognitive rehabilitation to optimise environment, support networks, self belief



# What is GREAT Cognitive Rehabilitation?

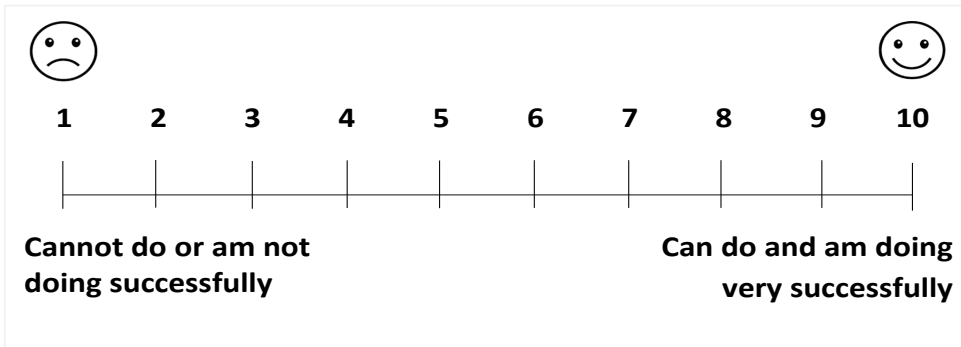
**GREAT Cognitive rehabilitation (GREAT-CR)** is an individual approach to enabling people living with dementia to function at the best level possible, remain engaged, and manage everyday activities.



# Setting goals and monitoring progress

Structured interview and accessible rating scale:

- Collaboratively identify areas to work on
- Define SMART goals: *Specific, Measurable, Achievable, Relevant, Timely*
- Rate current goal attainment
- Re-rate goal attainment to evaluate progress



## The Bangor Goal-Setting Interview

Research in Ageing and Cognitive Health, University of Exeter  
Linda Clare, Aleksandra Kudlicka and Sharon M Nelis  
Version 2 2016

Interviewee ID	Date of birth	Gender	Date of initial assessment
Interviewer			
Informant (where applicable – state nature of relationship)			
Planned dates of follow-up assessments:	Follow-up 1	Follow-up 2	Follow-up 3
Actual dates of follow-up assessments:	Follow-up 1	Follow-up 2	Follow-up 3
Dates of planned contacts (e.g. therapy or mentoring sessions) if applicable			

### STRUCTURE OF THE INTERVIEW

**Step 1:** Identifying areas to address (initial assessment only)

**Step 2:** Setting SMART goals (initial assessment only)

**Step 3:** Rating attainment (step 3a, initial and follow-up assessments), and importance and readiness to change (step 3b, initial assessment), in relation to each goal

**Step 4:** Assigning goal attainment descriptors to current attainment level (follow-up assessment only)

Instructions for completion are provided at each step.

Prior to carrying out the interview, the interviewer should be familiar with the detailed instructions provided in the *Bangor Goal-Setting Interview Manual*.

## Why are goals important?

Setting specific goals produces better performance than simply telling people to do their best

## Why do goals stimulate and improve performance?

- Goals direct attention towards relevant activities
- Goals produce greater effort: provide a focus for effort, enhance persistence and prolong effort
- Goals help to identify useful strategies as people draw on their repertoire of skills to meet the challenge

(Locke & Latham, 2002)

# GREAT Cognitive Rehabilitation Goal Setting

identifies with the person with dementia what is important to them that will impact on their everyday activities of daily living

uses the SMART criteria: Specific; Measurable; Attainable; Relevant; Time-limited

involves the care partner in discussion about potential goal

# Examples of specific goals that people successfully worked on

- John overcame the fear of using his mobile phone that was undermining his independence
- Doris regained the confidence to collect her pension from the post office, and learned to stay safe by remembering to lock her door at night
- Shahid started taking photographs again, and felt more able to take part in family conversations at mealtimes
- Gareth became able to cook his own meals without burning the food, and could remember his granddaughter's name
- June learned to find her way back to her room from the Care Home dining room and became less distressed

# What does the CR Practitioner do?

## Uses 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 be able to do or manage better (goal)
- What the person needs to be able to do in order to attain the goal
- Where there is a mismatch between what the person can do and what the goal requires, and where and why things go wrong

## Uses 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

# The GREAT CR Plan

- ✓ Draws on information gathered during the assessment
- ✓ Addresses the Goal identified by the person with dementia
- ✓ Is jointly agreed with the person and their care partner
- ✓ Uses a solution-focused approach
- ✓ Selects the techniques and strategies to work towards achieving the Goal
- ✓ Plans the time to work on the Goal

# GREAT Cognitive Rehabilitation Methods

## Compensatory strategies

- Remove the need to rely on the impaired ability
- Simplify the activity
- Uses memory aids
- Manages the environment

## Enhanced Learning Techniques

- Uses remaining abilities
- Requires time and effort
- Helpful for goals that are really important to the person

## Enhanced Learning Techniques for engaging in activities

- Graded activity, modelling, and action-based learning
- Prompting and fading
- Introducing assistive devices ('memory aids')
- Adapting the environment
- Expanding rehearsal

## Enhanced Learning Techniques for learning or re-learning information

- Chunking
- Elaboration
- Mnemonics
- Prompting and Fading Prompts
- Expanding rehearsal

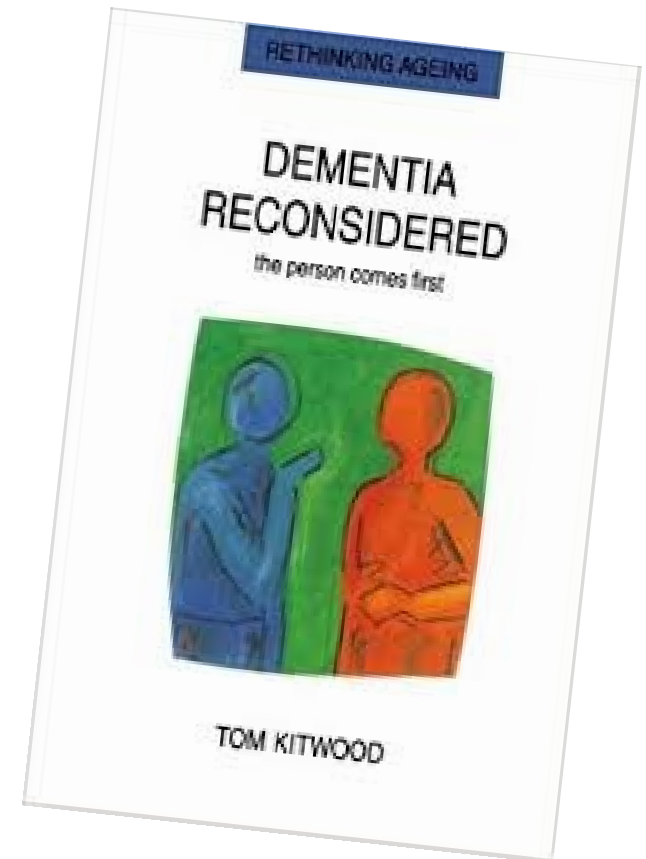
People differ in what works best, so a range of strategies should be tried to identify the most helpful for each person

# The concept of Rementia

**“The evidence for a more optimistic view of dementia is very fragmentary yet. Nevertheless, the general inference to be drawn from research to date is how much has been achieved through interventions that are only relatively modest; if improvements were consistent and throughout the entire context of dementia, we might reasonably expect to see much more than this.**

**We are very far from having reached the limits that are genuinely set by the structural state of the brain”**

Professor Tom Kitwood, 1997 (page 64)



# The GREAT trial

## Goal oriented Rehabilitation of Early Alzheimer's Trial

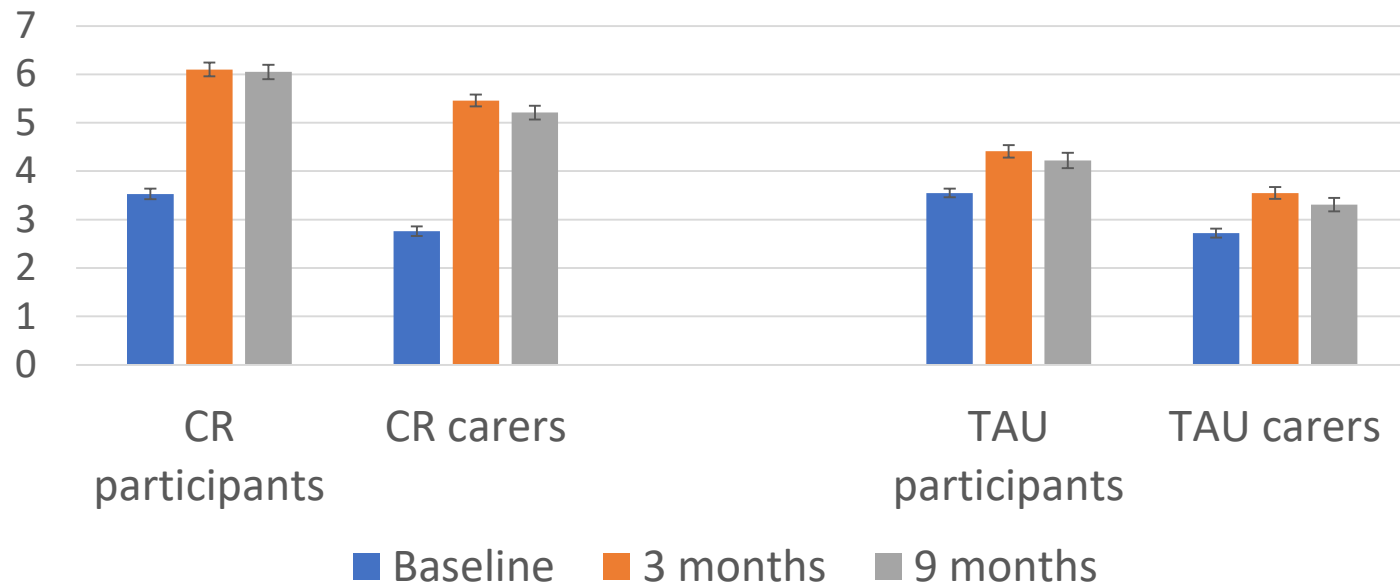
**Aim:** to find out whether CR is beneficial for people with early-stage AD, VaD or mixed dementia

**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



## Did people improve on their goals?



# Could CR be offered by NHS Trusts, homecare or care home providers?

Alzheimer's Society funded study 2017-2020

- Introducing **GREAT into practice (GREAT iP)** in 15 partner organisations providing health or social care services
- 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
- Finding out whether the benefits are the same when CR is part of normal service provision

# An early look at GREAT-iP results for people living in their own homes

## Initial implementation in 4 NHS Trusts

29 people with dementia had an average of 6 visits

### Views about CR

People with dementia (n = 26):

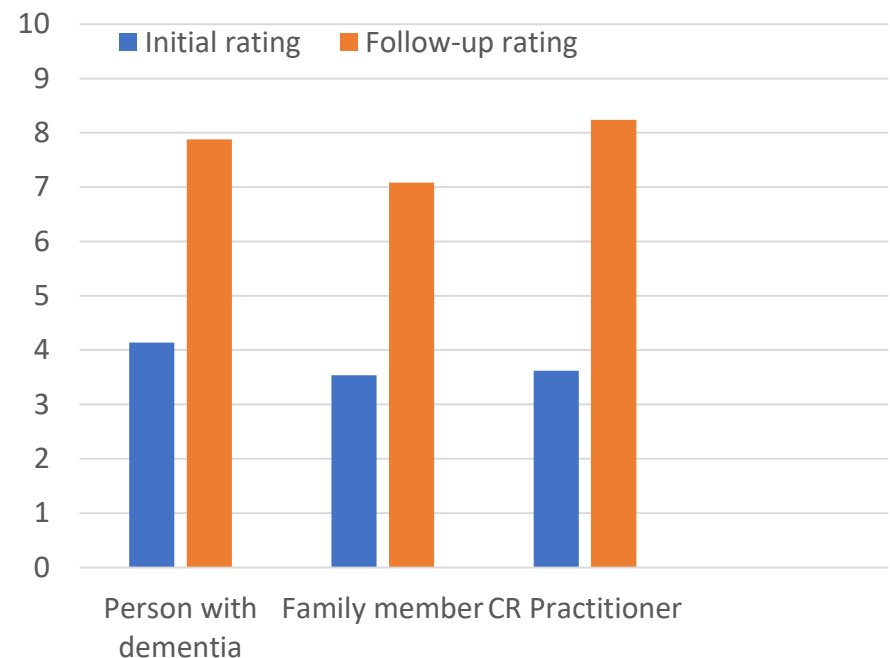
Useful – 96%

Would recommend to others – 100%

Carers (n = 25):

Useful – 100%

Would recommend to others – 100%



Ratings for 29 people with dementia

## The GREAT iP trial at Sunrise Senior Living (Nov 2018 -19)

4 Sunrise Homes participated in the GREAT-iP study

2 Homes had an additional 20 hours of Occupational Therapist to deliver CRT

2 Homes delivered CRT without additional hours or professionals:

- Senior Care Assistants
- Activity Co-ordinator

GREAT CR delivered to each resident twice weekly in 1 hour sessions for 10 weeks

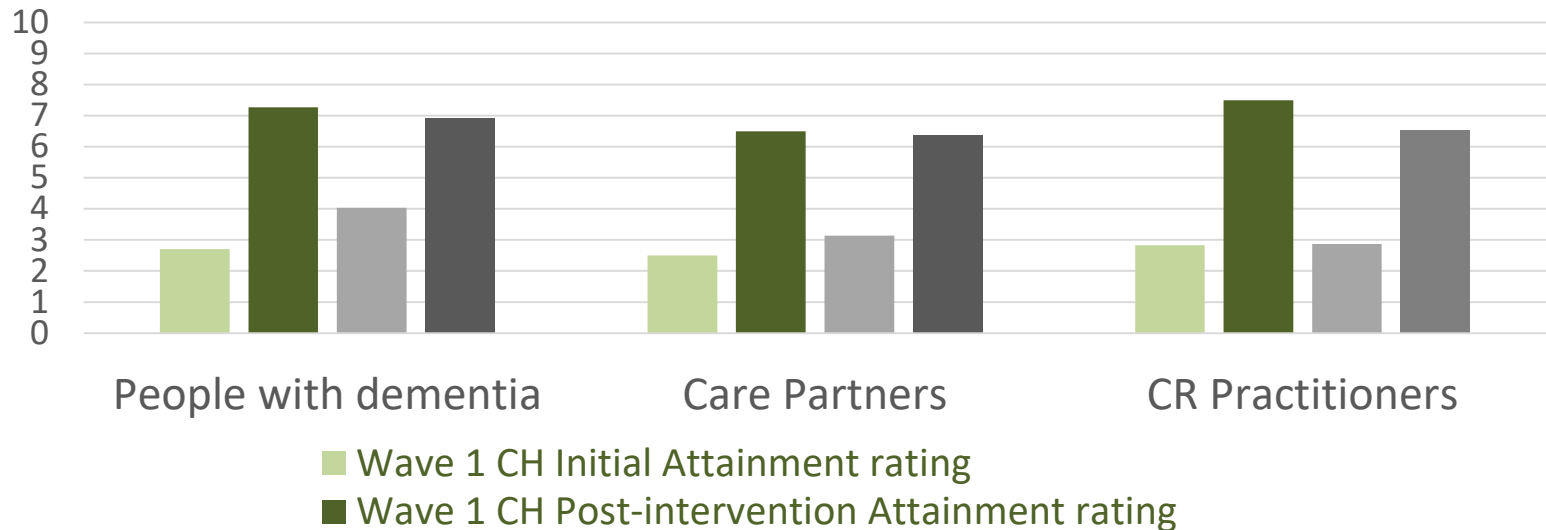
In addition to the Trial data, Sunrise also collected internal data on:

- Resident well-being (Bradford Well-being Profile)
- Resident cognitive function ability (Pool Activity Level (PAL) Instrument)



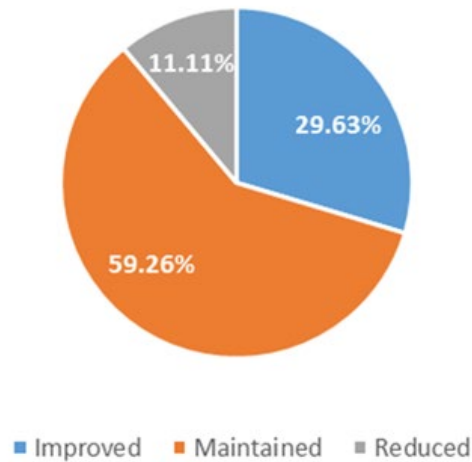
## BGSI attainment ratings

Wave 1 Care homes vs GREAT trial

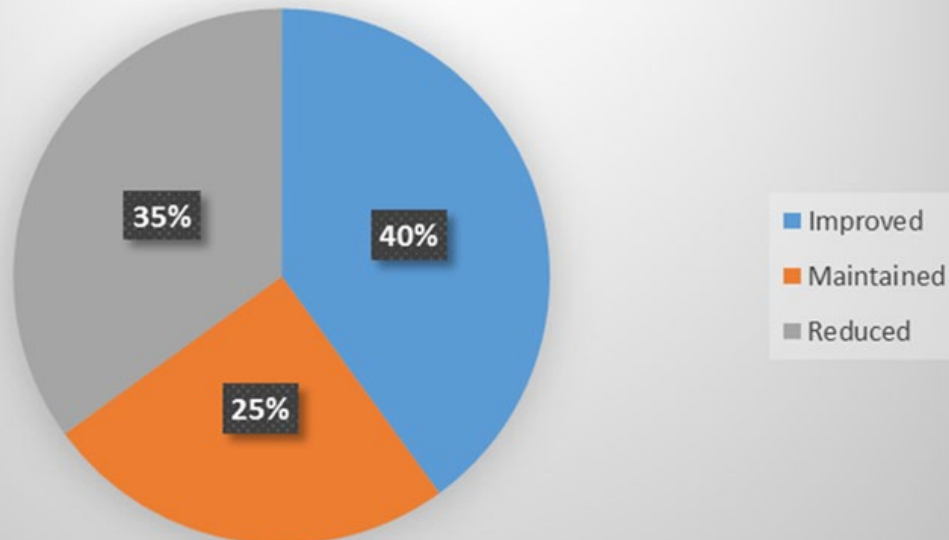


	People with dementia	Care Partners	CR Practitioners
Initial Attainment - Care homes	2.71 (n=29)	2.50 (n=6)	2.83 (n=30)
Post-intervention Attainment - Care homes	7.27 (n=30)	6.50 (n=4)	7.50 (n=30)
Initial Attainment - Trial	4.03 (n=233)	3.14 (n=233)	2.87 (n=233)
Post-intervention Attainment - Trial	6.92 (n=214)	6.37 (n=211)	6.52 (n=215)

### PAL Cognitive Levels of CRT Participants



### Resident Wellbeing Levels



# Views of people with dementia and care partners (feedback forms posted to Exeter)

	People with dementia, n=26	Care partners, n=25
Did you find the GREAT Cognitive Rehabilitation sessions useful?		
Yes, very useful	19 (73.1%)	17 (68.0%)
Yes, rather useful	6 (23.1%)	8 (32.0%)
No, not very useful	1 (3.8%)	0
Would you recommend GREAT Cognitive Rehabilitation?		
Yes	26 (100)	25 (100)

# Views of people with dementia and care partners

## (feedback forms posted to Exeter)

Open ended questions:

- People with dementia liked GREAT CR because it was useful, interactive, and there was someone who was actually coming to help.
- GREAT CR made a difference as they learnt or improved knowledge and abilities and gained confidence.
- In addition, care partners acknowledged that they learnt themselves skills for better supporting their loved ones and had good experience of GREAT CR overall.

*"I didn't know how to use my mobile phone and now I do."*

*"More confidence."*

*"More secure."*

*"Boosted my feelings about myself."*

(Persons with dementia)

*"Husband able to research more and feels more independent."*

(Care partner)

# Acknowledgements

- All the people living with dementia and family members who participated in the studies described
- Our partner organisations
- Our PPI representatives
- Professor Linda Clare, Dr Ola Kudlicka, Dr Rachel Collins, Suzannah Evans, the GREAT and CORD-PD trial teams, and the GREAT-iP project team
- Our funders: National Institute of Health Research, Alzheimer's Society, and Health and Care Research Wales



  
National Institute for  
Health Research



Kent and Medway  
NHS and Social Care Partnership Trust  
Northumberland, Tyne and Wear  
NHS Foundation Trust



# Further information about GREAT

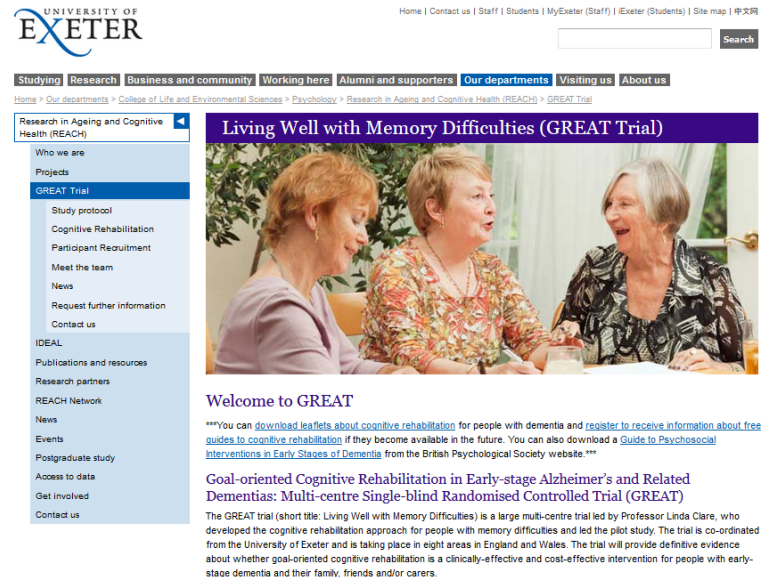
REACH: Research in Ageing and Cognitive Health  
School of Psychology, University of Exeter

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The screenshot shows the University of Exeter website. The top navigation bar includes links for Home, Contact us, Staff, Students, MyExeter (Staff), Exeter (Students), Site map, and 中文网. Below this is a search bar. The main navigation menu includes Studying, Research, Business and community, Working here, Alumni and supporters, Our departments, Visiting us, and About us. The breadcrumb trail reads: Home > Our departments > College of Life and Environmental Sciences > Psychology > Research in Ageing and Cognitive Health (REACH) > GREAT Trial. The left sidebar contains a menu for 'Research in Ageing and Cognitive Health (REACH)' with options: Who we are, Projects, GREAT Trial (selected), Study protocol, Cognitive Rehabilitation, Participant Recruitment, Meet the team, News, Request further information, and Contact us. Below this is a section for IDEAL with links for Publications and resources, Research partners, REACH Network, News, Events, Postgraduate study, Access to data, Get involved, and Contact us. The main content area is titled 'Living Well with Memory Difficulties (GREAT Trial)' and features a photograph of three elderly women sitting at a table. Below the photo is a 'Welcome to GREAT' section with a paragraph of text and a link to download leaflets. The text states: '\*\*\*You can download leaflets about cognitive rehabilitation for people with dementia and register to receive information about free guides to cognitive rehabilitation if they become available in the future. You can also download a Guide to Psychosocial Interventions in Early Stages of Dementia from the British Psychological Society website.\*\*\*' Below this is the title 'Goal-oriented Cognitive Rehabilitation in Early-stage Alzheimer's and Related Dementias: Multi-centre Single-blind Randomised Controlled Trial (GREAT)' and a paragraph describing the trial: 'The GREAT trial (short title: Living Well with Memory Difficulties) is 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.'

[www.exeter.ac.uk/great](http://www.exeter.ac.uk/great)