

# International Encyclopedia of Rehabilitation

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# **Cognitive rehabilitation and people with dementia**

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## **Summary**

Cognitive rehabilitation (CR) aims to enable people with cognitive impairments to achieve their optimum level of well-being by helping to reduce the functional disability resulting from damage to the brain. Central to this process is the collaborative identification of personally-meaningful goals and the development of interventions to address these goals. CR interventions draw upon a mixture of approaches aimed at restoration of function, implementation of compensatory strategies and environmental modification, and these can be integrated with approaches directed at dealing with the emotional responses to impairment and other psychosocial difficulties to provide an holistic rehabilitation framework. While initially developed primarily for people with non-progressive brain injury, this approach is equally applicable to people with progressive conditions such as Alzheimer's disease (AD). Although this work is still at a relatively early stage, the first randomised controlled trial has now been completed. This chapter reviews the application of the CR approach for people with AD and considers the evidence for its effectiveness. The available evidence suggests that CR has the potential to bring about changes in behaviour, enhance well-being and maintain involvement in daily life.

## **Key words**

Alzheimer's disease; awareness; behaviour; disability; episodic memory; generalisability; goal-setting; neuropsychological rehabilitation; procedural memory; randomised controlled trial

## **What is cognitive rehabilitation?**

Rehabilitation involves 'enabling people who are disabled by injury or disease to achieve their optimum physical, psychological, social and vocational well-being' (McLellan 1991, p. 785). Cognitive rehabilitation applies this concept specifically to people with cognitive impairments (Mateer 2005), taking into account the particular needs and challenges resulting from damage to the brain. Cognitive rehabilitation interventions aim 'to enable clients or patients, and their families, to live with, manage, by-pass, reduce or come to terms with deficits precipitated by injury to the brain' (Wilson 1997, p. 488). Where the neurological damage cannot be ameliorated,

there is still scope to reduce the resulting disability (limitations on engaging in activity) and handicap (restrictions on social participation) (World Health Organisation 1980, 1998), and to address any excess or unnecessary disability arising from secondary responses to the situation, for example depression or loss of self-esteem and self-confidence. The cognitive rehabilitation approach was developed throughout the 20th Century, with new developments stimulated in particular by the needs of brain-injured soldiers in the two World Wars (see Wilson 2008 for a comprehensive review). Recent shifts in emphasis have led to a particular focus on goal-setting in planning rehabilitation programmes, with clients involved in identifying personally-meaningful goals, and an acknowledgement of the need for an holistic approach that addresses cognitive, emotional and psychosocial factors in an integrated manner (Wilson 2008).

Cognitive rehabilitation interventions may involve a mixture of approaches aimed at restoration of function, implementation of compensatory strategies and environmental modification, and these can be integrated with approaches directed at dealing with the emotional responses to impairment (Mateer 2005) and other psychosocial difficulties to provide an holistic neuropsychological rehabilitation framework. Theories, models and methods from neuropsychology, cognitive psychology, and behavioural psychology, and perspectives from psychodynamic and systemic therapies, combine to create a rehabilitation framework that takes account of the individual's unique personal context. Interventions aim to tackle directly those difficulties that are considered most relevant by the person and family. Central to this process is the identification of realistic personal goals and needs. These are selected collaboratively wherever possible. The aim is to target areas where cognitive difficulties are impacting on everyday well-being. Specific interventions are designed to address these goals, using evidence-based methods and techniques. Emotional responses are addressed throughout. This approach is essentially a highly individualised, personalised one, acknowledging the heterogeneity of both underlying impairments and individual situations and responses. While the individual focus is paramount, various formats and modalities may be adopted in the process of working towards achievement of rehabilitation goals. Similarly, a range of health professionals may be involved. While initial professional training in either clinical psychology, neuropsychology or occupational therapy is most likely to provide the necessary skills, relevant principles can be learned by staff from a range of professional backgrounds.

## **Why is cognitive rehabilitation relevant for people with dementia?**

While initially developed for people with non-progressive brain injury, cognitive rehabilitation is equally applicable to people with progressive conditions such as Alzheimer's disease and other dementias, at any stage or degree of severity, although the focus will differ as priorities change over the course of the disorder and may shade into a palliative care approach towards the end of life (Clare 2008; Wilson 2008). It is appropriate to think of dementia in terms of disability rather than simply disease. The manifestation and progression of dementia in any one individual are influenced by a number of factors alongside the progression of neurological impairment; these include personality, biographical experience, social relationships, communication and interaction, and environmental context (Kitwood 1997). Thus, the expression of

symptoms may be exacerbated by unfavourable interactions and surroundings, or ameliorated by a more positive context. Negative contexts can contribute to producing unnecessary excess disability (Reifler and Larson 1990). Biological, psychological and social aspects of the condition must all be considered. The important distinction between underlying impairment at the neurological level on the one hand, and limitations on engaging in activity or on social participation on the other, as emphasised in the World Health Organisation model of disability (World Health Organisation 1980, 1998) is highly relevant to dementia. In dementia, as in other conditions, levels of activity and participation are influenced by personal and social context, and do not follow directly or straightforwardly from brain pathology (Kitwood 1997). Therefore, there is a great deal of scope for the application of cognitive rehabilitation to assist people with dementia and their families.

Many types of intervention for the person with dementia or the family might be construed as broadly 'rehabilitative' in nature in the sense that they aim to improve well-being in some sense, but this broad application of the term is probably unhelpful. Labelling many existing interventions as forms of 'rehabilitation' tends to obscure the importance of the careful application of a rehabilitation philosophy and method, and of the essentially individualised nature of the approach. Similarly, various forms of cognition-focused intervention, such as cognitive training approaches that aim to improve aspects of performance on cognitive tasks through repeated practice on standard tasks, can be distinguished from individualised, goal-oriented cognitive rehabilitation interventions that aim to limit disability and support everyday functioning (Clare, Woods, Moniz-Cook, Spector, and Orrell 2003).

### **What kind of assessment is needed?**

Implementing cognitive rehabilitation requires a careful assessment of the person's neuropsychological profile to establish current strengths and difficulties. This will be important in selecting specific methods and strategies. For example, awareness of the presence of perceptual difficulties would suggest caution in the use of visual cues. A general knowledge of the likely pattern of impaired and relatively preserved functions for the given stage of dementia is valuable; for example it can be anticipated that episodic memory will generally be severely affected in the early stages of Alzheimer's disease, while procedural memory will be relatively well preserved. However, given the heterogeneity of presentation, individual assessment remains important. Alongside the neuropsychological profile, assessment of functional ability is vital. Additionally, assessment of emotional reactions, personal resources and coping style, and of the social context including any family relationships or involvement is needed. Attention should also be given to subjective experience and awareness of difficulties. The extent to which the individual is able or willing to acknowledge difficulties will affect motivation to engage in intervention. Building up a picture of the individual in context provides a basis for collaborative identification of rehabilitation goals.

### **How are rehabilitation goals identified and addressed?**

Individualised cognitive rehabilitation interventions aim to tackle directly those issues considered relevant and important by the person with dementia and his/her family members or supporters. Rehabilitation goals relate to areas that are currently causing difficulty or concern, or reflect areas where the participant would like to see

improvement. Where the goals of the person and the family member differ markedly, careful and sensitive negotiation is needed to reach a consensus or compromise that is acceptable to both parties. Interventions focus directly on real-life, everyday situations. Generalisability of intervention effects from one setting to another is always a challenge in rehabilitation and this problem can be circumvented by conducting interventions in the setting where the adapted behaviour or new skills will need to be used.

Goals can be identified through discussion or by using a structured assessment format such as that provided by the Canadian Occupational Performance Measure (COPM; (Law et al., 2005). This samples a range of relevant domains and provides a method of rating performance and satisfaction with performance that can be used to evaluate progress. Goals might focus directly on the impact of cognitive difficulties in life; for example, participants might aim to improve their ability to remember important events during the day or keep track of important personal belongings, or to take in and retain important personally-relevant information. However, some goals may have a broader focus; for example, the participant might express a wish to resume previously-enjoyed activities, or to take up new activities so as to increase social contact.

Once a goal has been agreed, the therapist can then select from available evidence-based strategies in order to devise a personalised intervention. The following brief overview outlines some of the most frequently-used strategies:

1. Facilitating remaining episodic memory functioning. Where the aim is to build on the remaining episodic memory ability to encourage learning of important new information, or re-learning of previously-known information, a number of guiding principles can be followed. These include providing support at both encoding and retrieval (Bäckman 1992), ensuring effortful processing (Bird and Luszcz 1993), reducing errors during the learning process (Clare, Wilson, Breen, and Hodges 1999; Clare et al. 2000), and encouraging encoding through multiple sensory modalities (Karlsson et al., 1989). Specific methods include spaced retrieval (Camp 1989), cueing (Clare and Wilson 2004; Clare, Wilson, Carter, Roth, and Hodges 2002), simple mnemonics (Clare et al. 1999), encouraging semantic processing of material (Bird and Luszcz 1991, 1993) and the use of subject-performed tasks as an aid to encoding (Bird and Kinsella 1996).
2. Supporting procedural memory. Where the aim is to improve or restore the ability to carry out selected activities of daily living, action-based learning can be used (Hutton, Sheppard, Rusted, and Ratner 1996). Prompting methods can be used to encourage and support performance of an activity. A schedule of prompts can be devised on the basis of a detailed task analysis; prompts may be verbal or physical. Once performance is well-established, prompts can be faded out. Approaches of this kind can be useful when introducing new external memory aids.
3. Supporting semantic knowledge. Approaches used with people who have semantic dementia include repeated rehearsal combined with contextual

4. Addressing risky or problematic behaviours. This is especially relevant for people with frontal dementia, and a range of behavioural and environmental modifications can be employed to address problematic behaviours while maintaining the person's quality of life (Lough and Hodges 2002).

The process of setting and addressing goals proceeds through a number of stages, which can be summarised as follows:

1. Determine whether the person is able to identify something that s/he would like to be different.
2. Identify the area to focus on – for example, memory difficulties, participation in activities, or family relationships,
3. Identify the specific issue to focus on – for example, remembering the names of people met when participating in an activity,
4. Establish the baseline level of performance.
5. Identify the goal expressed in clear behavioural terms.
6. Identify what level of performance will indicate that the goal is (a) wholly or (b) partially achieved.
7. Plan the intervention to address the goal, using appropriate methods and techniques.
8. Implement the intervention, with appropriate attention to emotional responses and contextual issues.
9. Monitor progress and adjust the intervention if necessary.
10. Evaluate the outcome of the intervention and decide on any further steps to be taken.

This approach, while focused on specific measurable goals, is conducted in a flexible manner. The person's beliefs about his/her situation will be highly relevant during rehabilitation and may need to be addressed (Cicerone 1991). Working on areas that may be difficult or challenging is likely to prompt emotional reactions and these require sensitive responses. The beliefs, emotions and needs of caregivers also need to be considered, and appropriate support for carers should be provided.

## **Is cognitive rehabilitation effective for people with dementia?**

Individualised rehabilitation approaches targeting relevant and personally-meaningful aspects of everyday functioning have demonstrated significant benefits in single-case

and small-group intervention studies (Bird 2001; 2000; Clare et al. 1999; Clare et al. 2000; Clare, Wilson, Carter, and Hodges 2003; Clare, Wilson, Carter, Hodges, and Adams 2001; Josephsson et al. 1993). There is no one single specific correct approach or method, and cognitive rehabilitation may be applied in various ways in various settings. However, the application of this approach for people with dementia is still at a relatively early stage, and rigorous evaluation is essential in order to provide a sound evidence base for further development of this approach. We have developed a structured yet flexible protocol suitable for evaluation in a clinical trial (Clare 2007). In this program, cognitive rehabilitation sessions take place for 60 – 90 minutes a week over 8 weeks, so that each participant receives 8 sessions of therapy. These sessions typically take place in the participant's own home, to facilitate implementation of strategies in the everyday setting. Participants are encouraged to work on goals and practice strategies between sessions. The intervention addresses six areas:

1. *Rehabilitation goals.* The aim is to identify and work on one or two personal rehabilitation goals. Goals are identified at the start of therapy by following the process outlined above, and an individual approach to addressing these goals is designed and implemented over the course of the sessions. Work on personal goals forms the central element of the program and continues throughout all sessions, supported by the other components of the program.
2. *Practical strategies.* This component involves a review of the participant's current use of memory aids and practical coping strategies, explores whether it might be possible to build on these to promote more efficient use, and supports the introduction of new aids or strategies where appropriate (Bourgeois 1992).
3. *Memory.* The therapist introduces techniques for learning new associations and information, provides practice in these, identifies the person's preferred strategy, and encourages the wider application of this strategy in everyday life.
4. *Attention and concentration.* Practice is provided in maintaining attention and concentration while processing information, drawing on rehabilitation methods devised for people with impairments of executive function (Levine et al. 2000).
5. *Stress management.* The person's current ways of coping with stress and anxiety are explored, suggestions are made to build on these strategies, and relevant practice is provided using simple stress management and relaxation techniques (Suhr, Anderson, and Tranel 1999).
6. *Family involvement (where possible).* If the participant has a spouse or other family member or carer, and accepts his/her involvement, that person is invited to join the last 15 minutes of each session. This part of the session is devoted to reviewing the content of the session, agreeing the home practice to be undertaken in preparation for the next session, and discussing ways of facilitating progress with the personal rehabilitation goals. Family involvement helps to ensure the intervention has maximum impact in the everyday context.

This programme was recently compared in a randomised controlled trial to Relaxation Therapy (RT) and a no-treatment control condition (NT) (Clare et al. submitted). As far as we are aware, this is the first clinical trial of individual, goal-oriented cognitive rehabilitation for people with dementia. Following the intervention, people in the CR group rated their performance, and satisfaction with performance, of personal rehabilitation goals significantly better, while the other two groups showed no change. For a sub-group of participants who underwent fMRI scanning, these significant gains were mirrored in changes in brain activation while carrying out a memory task. Similar effects were found in a single-case study of an individual with MCI who completed the CR program (Clare et al. 2009). These findings will need to be confirmed by future research, but they do suggest that CR can produce clinically-significant benefits for people with early-stage AD.

## **What conclusions can we draw from the work that has been done so far?**

Cognitive rehabilitation is a relatively new approach to improving well-being for people with dementia and their families, and at present only preliminary evidence regarding efficacy is available. However, this preliminary evidence suggests that CR does have the potential to bring about changes in behaviour, enhance well-being and maintain involvement in daily life. Psychosocial interventions of this kind can be provided alongside pharmacological treatment, and it is possible that these two approaches can complement one another to optimise benefits for the person with dementia. There are a great many questions still to be answered, but the existing evidence provides a valuable basis for further development of this approach. Certainly, given the multiplicity of the challenges engendered by the complex processes we describe as 'dementia', CR will constitute only one small part of the total picture as regards appropriate and beneficial interventions. However, it can provide a useful guiding approach to intervention at the psychosocial level, ensuring that the person with dementia is understood in his/her social and environmental context and that individual needs and goals remain central.

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